

**CLOSE RELATIONSHIPS AMONG  
YOUNG ADULT SURVIVORS OF CHILDHOOD CANCER:  
A QUANTITATIVE AND QUALITATIVE ANALYSIS**

by

Amanda L. Thompson

B.A. in Psychology, Georgetown University, 2000

M.S. in Clinical-Developmental Psychology, University of Pittsburgh, 2003

Submitted to the Graduate Faculty of

University of Pittsburgh in partial fulfillment

of the requirements for the degree of

Doctor of Philosophy

University of Pittsburgh

2007

UNIVERSITY OF PITTSBURGH  
FACULTY OF ARTS AND SCIENCES

This dissertation was presented

by

Amanda L. Thompson

It was defended on

July 31, 2006

and approved by

Susan B. Campbell, Ph.D.

Linda J. Ewing, Ph.D., RN

Carl N. Johnson, Ph.D.

William M.P. Klein, Ph.D.

Robert B. Noll, Ph.D.

Anna L. Marsland, Ph.D., RN

Dissertation Director

# **CLOSE RELATIONSHIPS AMONG YOUNG ADULT SURVIVORS OF CHILDHOOD CANCER: A QUANTITATIVE AND QUALITATIVE ANALYSIS**

Amanda L. Thompson, Ph.D.

University of Pittsburgh, 2007

The growing body of research focusing on the long-term sequelae of diagnosis and treatment for childhood cancer suggests that while the majority of survivors are not at increased risk for psychopathology, many experience persistent problems in other domains that greatly affect quality of life (QoL). Social well-being, a construct that includes the development and maintenance of interpersonal relationships and issues of affection and sexuality, has been somewhat neglected in the late-effects literature. As such, a multi-method, developmentally sensitive study was conducted 1) to assess whether childhood cancer survivors experience difficulties in their close relationships during young adulthood, 2) to characterize the nature of these difficulties, 3) to identify who may be at risk for long-term social sequelae, and 4) to document survivors' own perceptions of their interpersonal relationships.

Sixty young adult (18-25years old) survivors of childhood cancer and 60 controls without a history of chronic illness completed an online assessment of their friendship and romantic relationships. In addition, a subsample of 18 female survivors participated in a follow-up qualitative interview. Quantitative analyses revealed that relative to controls, survivors were involved in fewer romantic relationships over the past five years and reported being significantly more distressed at the dissolution of those relationships. High trait anxiety, male gender, an older age of diagnosis, and higher treatment intensity emerged as significant risk factors for a host of relationship difficulties within the survivor sample, including lower relationship satisfaction, lower levels of reported intimacy, greater fear of intimacy, more conflict, and more

distress at break-up. Finally, qualitative findings highlighted relationship issues not captured by the quantitative measures, including cautiousness with personal self-disclosure, self-consciousness as a result of treatment-related physical changes and medical sequelae, and concerns about fertility. In light of the inconsistencies between quantitative and qualitative findings, this study emphasizes the need for more sophisticated measures of survivors' social QoL. Limitations of the study (related to sampling and measurement) are discussed, and a number of future directions are suggested.

## TABLE OF CONTENTS

LIST OF TABLES.....	viii
LIST OF FIGURES .....	ix
ACKNOWLEDGMENTS .....	x
1. Introduction.....	1
1.1. Quality of Life.....	2
1.2. Long-term Effects of Childhood Cancer on Young Adult Relationships.....	3
1.2.1. The Infant with Cancer .....	4
1.2.2. The School-aged Child with Cancer .....	5
1.2.3. The Adolescent with Cancer .....	5
1.2.4. Beyond Adolescence.....	6
1.2.5. Social Problems among Child/Adolescent Survivors .....	7
1.2.6. Social Problems among Young Adult Survivors .....	8
1.3. Relationship Quality .....	10
1.3.1. Primary Outcome Measures.....	11
1.3.1.1. Relationship satisfaction .....	11
1.3.1.2. Relationship duration/stability .....	11
1.3.1.3. Relationship conflict .....	12
1.3.2. Proposed Mediators of Relationship Quality .....	12
1.3.2.1. Expectations.....	13
1.3.2.2. Intimacy and fear of intimacy .....	14
1.4. Methodological Improvements on Previous Studies .....	15
1.4.1. Developmental Considerations .....	16
1.4.1.1. Age at diagnosis and treatment .....	16
1.4.1.2. Age at follow-up .....	17
1.4.2. Consideration of Additional Risk Factors.....	18
1.4.2.1. Pre-existing psychopathology .....	18
1.4.2.2. Gender.....	19
1.4.2.3. Treatment intensity .....	20
1.4.3. Incorporation of Qualitative Methods.....	20
1.5. Summary and Hypotheses.....	21
2. Method.....	24
2.1. Participants.....	24
2.1.1. Survivors.....	24
2.1.2. Controls.....	24
2.1.3. Demographics .....	25
2.2. Procedure .....	26
2.2.1. Initial Contact.....	26
2.2.2. Internet-based Assessment.....	26
2.3. Quantitative Measures .....	27
2.3.1. Demographics .....	27
2.3.2. Treatment Intensity .....	27
2.3.3. Relationship History .....	28

2.3.4.	Relationship Satisfaction .....	29
2.3.4.1.	The Relationship Assessment Scale (RAS) .....	29
2.3.4.2.	Quality of Marriage Index (QMI) .....	30
2.3.5.	Proposed Mediators .....	30
2.3.5.1.	Expectations .....	30
2.3.5.2.	Intimacy .....	30
2.3.5.3.	Fear of intimacy .....	31
2.3.6.	Proposed Moderators .....	32
2.3.6.1.	Gender .....	32
2.3.6.2.	Trait anxiety .....	32
2.4.	Qualitative Interview .....	32
2.5.	Data Analysis .....	33
2.5.1.	Quantitative Analysis .....	33
2.5.2.	Qualitative Analysis .....	34
3.	Results .....	35
3.1.	Quantitative Results .....	35
3.1.1.	Romantic Relationships .....	35
3.1.1.1.	Group differences on romantic relationship variables .....	35
3.1.1.2.	Moderation of relationship between childhood disease status and romantic relationship satisfaction .....	36
3.1.1.3.	Mediation of relationship between childhood disease status and romantic relationship satisfaction .....	37
3.1.2.	Friendship Relationships .....	37
3.1.2.1.	Group differences on friendship relationship variables .....	37
3.1.2.2.	Moderation of relationship between childhood disease status and friendship relationship satisfaction .....	37
3.1.2.3.	Mediation of relationship between childhood disease status and friendship relationship satisfaction .....	38
3.1.3.	Exploratory Analyses .....	38
3.1.3.1.	Age of diagnosis .....	38
3.1.3.2.	Treatment intensity .....	39
3.1.3.3.	Within-group analyses of romantic relationships .....	39
3.1.3.4.	Within-group analyses of friendships .....	40
3.2.	Qualitative Interview Findings .....	41
3.2.1.	Maturity and Perspective .....	42
3.2.1.1.	Influence on friendships .....	43
3.2.1.2.	Influence on romantic relationships .....	45
3.2.2.	Self-Disclosure .....	47
3.2.2.1.	Revealing cancer history .....	47
3.2.2.2.	Revealing emotions and personal thoughts .....	51
3.2.3.	Body Image .....	54
3.2.4.	Trust .....	56
3.2.5.	Honesty and Communication .....	58
3.2.6.	Fertility and Family Issues .....	59
4.	Discussion .....	62
4.1.	Summary of Findings .....	62

4.1.1.	Moderators of Relationship Outcomes .....	65
4.1.1.1.	Trait anxiety .....	66
4.1.1.2.	Age of diagnosis .....	67
4.1.1.3.	Treatment intensity .....	69
4.1.1.4.	Gender .....	70
4.2.	Study Limitations.....	70
4.2.1.	Measurement Considerations.....	70
4.2.2.	Sampling considerations .....	72
4.3.	Future Directions .....	74
4.4.	Clinical Implications and Conclusion.....	76
5.	References.....	78
	APPENDIX A: Qualitative Interview Conversational Guide.....	94
	APPENDIX B: Qualitative Interview Transcript Text .....	95
	APPENDIX C: Tables .....	112
	APPENDIX D: Figures.....	124

## LIST OF TABLES

Table 1	Survivor Illness and Treatment Variables .....	112
Table 2	Sample Demographics .....	113
Table 3	Descriptive Statistics for Study Measures .....	115
Table 4	Group Differences for Romantic Relationship Variables.....	116
Table 5	Correlation Matrix of Romantic Relationship Variables.....	117
Table 6	Moderation of Childhood Illness Group and Romantic Relationship Satisfaction .....	118
Table 7	Group Differences for Friendship Variables .....	119
Table 8	Correlation Matrix for Friendship Variables .....	120
Table 9	Moderation of Childhood Illness Group and Friendship Satisfaction .....	121
Table 10	Qualitative Interview Participants' Demographics and Illness and Treatment Variables, .....	122



## LIST OF FIGURES

Figure 1	Model of Relationship Quality .....	124
Figure 2	Mediation of the relationship between childhood disease status and relationship satisfaction .....	125
Figure 3	Interaction of childhood illness group and current age in the prediction of fear of intimacy.....	126
Figure 4	Interaction of childhood illness group and trait anxiety in the prediction of friendship satisfaction .....	127
Figure 5	Number of relationships in the last five years for controls and age of diagnosis survivor groups .....	128
Figure 6	Number of relationships in the last five years for controls and treatment intensity survivor groups .....	129
Figure 7	Romantic relationship satisfaction for controls and treatment intensity survivor groups .....	130
Figure 8	Friendship satisfaction for controls and treatment intensity survivor groups .....	131
Figure 9	Average level of distress at relationship end for controls and treatment intensity survivor groups .....	132
Figure 10	Interaction of age of diagnosis and trait anxiety in the prediction of romantic relationship satisfaction within the survivor sample.....	133
Figure 11	Interaction of age of diagnosis and trait anxiety in the prediction of fear of intimacy within the survivor sample.....	134
Figure 12	Interaction of gender and trait anxiety in the prediction of romantic relationship satisfaction within the survivor sample.....	135
Figure 13	Interaction of gender and trait anxiety in the prediction of conflict in romantic relationships within the survivor sample .....	136
Figure 14	Interaction of treatment intensity and trait anxiety in the prediction of intimacy within the survivor sample .....	137
Figure 15	Interaction of treatment intensity and trait anxiety in the prediction of romantic relationship satisfaction within the survivor sample.....	138

## ACKNOWLEDGMENTS

First and foremost, I would like to express my deepest appreciation to my advisor, Anna Marsland, for her never-ending support and encouragement. Her guidance over the past three years has been truly invaluable, and my accomplishments are only a reflection of her superior mentorship. I would like to thank Lin Ewing for allowing me to be a part of the ups and downs of intervention research and for sharing with me her unparalleled clinical skills. Thank you to Bob Noll for the mentorship that began before he even set foot in Pittsburgh, for the opportunity to work on his project, and for the hours of academic debate that have forced me to think more critically. I would also like to thank Sue Campbell, my teacher—in and out of the classroom—for over five years; I am in awe of your accomplishments. To Carl Johnson, for helping me navigate the new world of qualitative research, and Bill Klein, for the willingness to contribute his wisdom to my research, thank you.

I would like to acknowledge those who helped get this project off the ground: John Orefice, who helped me develop and design the website that made this study possible; Anita Yang, who assisted with the often-tedious project details without ever losing her smile; the CHP physicians and staff, including Dr. Jean Tersak, Dr. Kim Ritchey, Peg Moriello, and Shawna Harris; and all the survivors of childhood cancer who were so supportive of my efforts.

My heartfelt thanks goes out to Michael Marshall for his constant support, both personally and professionally, over the past five years. Besides providing me with hours of invaluable advice (and statistical consultation), he has always reminded me not to take life too seriously. Special recognition goes to Carrie Sheets, my writing partner for the past four months. Her humor has made this process a memorable one; it would not have been as much ‘fun’ without her.

I would like to thank my father, Stewart Thompson, my sister, Stephanie, and my brother-in-law, Chris, for their love and support over the years. In so many ways, they have helped me make it through. And last, but certainly not least, I would like to thank my mother, for showing me the true meaning of courage and for inspiring me everyday to live life to the fullest. This work, and everything I do, is dedicated to her memory.

## **1. Introduction**

Before the advances of modern treatment, childhood cancer was almost invariably life-threatening. Over the past three decades, however, new medications and more aggressive treatment regimes have dramatically improved survival rates for most types of childhood cancer. In fact, almost 80% of children currently diagnosed with cancer are predicted to become long-term survivors (American Cancer Society, 2005). As a result of this increased survivorship, the pediatric oncology literature has shifted its focus from cancer as a terminal disease to cancer as a chronic illness, and, as a result, the long term sequelae of diagnosis and treatment have become more salient. To date, the physical and cognitive late effects of treatment have been well documented (for reviews, see Bhatia, Blatt, & Meadows, 2004; Hewitt, Weiner, & Simone, 2003; Moore, 2005); however, there is still some uncertainty regarding the long-term psychosocial consequences of surviving childhood cancer.

The diagnosis and treatment of childhood cancer constitute a series of major life stressors involving significant life threat and disruption of family life, painful and intrusive medical procedures, repeated hospitalizations, and multiple school absences. It seems likely, then, that children treated for childhood cancer may experience long-term psychological and social consequences. Over the past decade, the body of literature documenting the psychosocial late-effects of treatment for childhood cancer has grown considerably, but findings have been inconsistent, with some studies reporting significant distress in individuals treated for childhood cancer (i.e., Mulhern, Wasserman, Friedman, & Fairclough, 1989; Sanger, Copeland, & Davidson, 1991; Zebrack et al., 2002), some finding no differences between survivors and population norms or non-diseased control groups (i.e., Kazak, Christakis, Alderfer, & Coiro, 1994; Kupst et al., 1995) and others even documenting better-than-normal mental health among survivors (Anholt, Fritz, & Keener, 1993; Elkin, Phipps, Mulhern, & Fairclough, 1997). Despite these inconsistencies, available research suggests that while the majority of

long-term survivors are not at increased risk for *psychopathology* (i.e. clinical diagnoses of PTSD, anxiety or depressive disorders), many experience persistent problems in other domains that greatly affect their quality of life, such as academic achievement, employment attainment, insurability, health-related concerns, and interpersonal relationships (Hays, et al. 1992; Langeveld et al., 2003; Langeveld, Grootenhuis, Voute, de Haan, & Van den Bos, 2004).

### **1.1. Quality of Life**

Considered an important outcome parameter in terms of clinical decision making and preventative/supportive intervention efforts, quality of life (QoL) is a composite of multidimensional factors including physical, psychological, and social well-being (Dolgin, Somer, Buchvald, & Zaizov, 1999). Physical QoL describes an individual's level of comfort and mobility and includes consideration of disease and treatment-related symptoms such as pain and fatigue; psychological QoL captures both positive and negative facets of mental health-- from enjoyment and happiness to anxiety and depression, from feelings of purpose and control over one's life to concerns of uncertainty and fear for the future. Social QoL includes fulfillment of social roles, development and maintenance of interpersonal relationships, real and perceived burden on the family, and issues of affection and sexuality. Despite its documented association with both physical and psychological well-being (Berkman & Syme, 1979; DeLongis, Folkman, & Lazarus, 1988), social QoL has been somewhat neglected in the literature on young-adult survivors of childhood cancer. The following study, then, focuses on this QoL component, with a particular emphasis on the nature of close relationships, both friendship and romantic.

Research consistently documents the contribution of interpersonal relationships to overall well-being, as people who have positive, lasting relationships have lower mortality rates and fewer psychological and physical health problems than people with weak social networks (Cohen, 2004;

DeLongis et al., 1988). If an individual cannot connect in a positive, intimate way with another human being, then he/ she is at increased risk for a variety of physical, interpersonal, and emotional difficulties (Baumeister & Leary, 1995; Levine, 1991; Prager, 1995). Specifically, difficulties with intimacy have been linked to many mental health disorders, more stress-related symptoms, and higher mortality rates (Baumeister & Leary, 1995). Of particular importance to cancer survivors, people who lack intimate relationships not only show depressed immunological functioning, but also are more likely to develop and have slower recovery from illness and to be at increased risk of relapse of physical disease (Cohen, 1988; Levine, 1991; Prager, 1995). As such, quality of intimate social connections and dissatisfaction with friendship and romantic relationships may be salient risk factors for a host of other psychological and physical problems among survivors of childhood cancer. To date, however, few empirical studies have focused on the nature of close relationships in this potentially vulnerable population. As such, the goals of this study are to 1) assess whether childhood cancer survivors experience difficulties in their close relationships, 2) characterize the nature of these difficulties and the processes involved, and 3) identify who may be at risk for long-term social sequelae. A focused look at friendship and romantic relationships will enhance current understanding of the experience of childhood cancer survivors and may aid health care professionals in developing strategies to help them adapt to the period of survivorship.

## **1.2. Long-term Effects of Childhood Cancer on Young Adult Relationships**

Why might one expect childhood cancer to have a lasting impact on the social relationships of survivors? A number of different pathways may be operating, and, as discussed in the following sections, these pathways likely vary according to the developmental stage of the child at the time of diagnosis and treatment. In general, specific features of the childhood cancer experience may pose a threat to the accomplishment of salient developmental tasks; failure to accomplish these tasks

compromises psychosocial maturity which, in turn, increases the risk of future adjustment problems (Stam, Grootenhuis, & Last, 2001), including difficulties in interpersonal relationships.

### **1.2.1. The Infant with Cancer**

In considering the impact of chronic illness during the period of infancy, researchers have focused on implications for parent-child attachment (see Eiser, 1993). Specifically, treatment for childhood cancer may jeopardize normal attachment processes between infant and mother through long periods of separation, the demands of additional caretaking tasks, a reduction in ‘fun’ time to play together, and increased maternal anxiety and depression. Factors that generally promote the development of a secure emotional relationship in infancy (i.e., consistent caregiving, intimate contact) may be compromised by the demands of the disease and treatment.

Attachment theory states that the quality of the first relationship is central to, and predictive of, future development because it establishes prototypic motives, needs, goals, and fears that persist beyond infancy (Bowlby, 1969). In the context of the parent-child relationship, children learn how to initiate and maintain satisfying and warm interactions and how to interpret the needs and feelings of others. They develop ‘internal working models’ of close relationships that come to structure and direct their behaviors in subsequent social interactions, including romantic relationships and intimate friendships. Disturbances in infant-caregiver attachment relations, then, ought to predict intimacy problems later in life (Hazan & Shaver, 1987). Early attachment difficulties have been found to adversely affect middle-childhood peer relations in a manner that may foretell intimacy problems in adulthood (Buhrmester & Furman, 1986), while secure attachment representations have been found to be related to friendship duration and quality, greater relationship satisfaction, more self-disclosure, and the maintenance of romantic relationships (Bippus & Rollin, 2003; Grabill & Kerns, 2000; Miller & Hoicowitz, 2004).

### **1.2.2. The School-aged Child with Cancer**

The school environment requires children to negotiate the social world of peers. It offers children opportunities for play and social interaction, teaches social norms and values, and provides a sense of social belonging to the culture that maintains these norms and values. Unfortunately, children with cancer have the poorest school attendance rates of many chronic illnesses and conditions, including renal disease, cardiac and orthopedic conditions, and asthma (Charlton et al., 1991; Vance & Eiser, 2002). While school absence tends to decline after the first year post-diagnosis (Vance & Eiser, 2002), children may still miss substantial portions of their early education (and therefore socialization) experience.

Children who return to school while still on treatment or shortly after treatment completion must cope with illness-imposed physical limitations and treatment-related fatigue. As a result, they may be excluded from school activities, sports, and games, may lose opportunities for normal interactions with peers both in and out of school, and due to treatment-related physical changes (i.e., weight gain as a result of steroids and/or hair loss as a result of chemotherapy) may become easy targets of teasing. Consequent social isolation may prevent adequate integration into the world of peers, thereby changing the course of social development among survivors and compromising more long-term social adaptation.

### **1.2.3. The Adolescent with Cancer**

The multiple challenges, changes, and stressors that adolescents confront during puberty may be intensified substantially by the diagnosis and treatment of cancer. Developmentally normal adolescent concerns of autonomy-seeking, identity consolidation, peer relations, self-esteem, sexuality, and future orientation may be complicated by the dependency of the patient role, the isolating effects of the illness, treatment-related physical changes and bodily discomfort, and an unpredictable disease course that may include future relapse (Apter, Faberstein, & Yaniv, 2003; Kazak & Stuber, 1999).

Instead of making strides to differentiate from the family unit, adolescents with cancer are often forced to rely heavily on their parents (Kazak, 1994) for emotional and material support. Developmentally appropriate desires to test societal norms within the context of the peer group may be delayed. As a result, the chronically ill adolescent may not be able to face the full developmental challenges of identity formation and independence, which may produce successive delays in maturation and impede future capability of merging with another in a truly intimate relationship (McAnarney, 1984).

#### **1.2.4. Beyond Adolescence**

Cancer-specific worries about the future may continue to contribute to the social difficulties reported by survivors, as perceptions of future vulnerability to illness and worry over fertility status are highly prevalent among survivors. Studies indicate that at least 50% of long-term survivors express a fear of recurrence—i.e., that the malignancy may reappear or a new malignancy may develop after the successful termination of treatment (Henderson, 1997; Langeveld et al., 2004). With fertility rates among survivors ranging from 40 to 85% of expected rates (Herold & Roetzheim, 1992), they also report significant worry about their reproductive capacities (Zeltzer, 1993), and compared to adults without a history of cancer, they express more concern over the health of their future children; (Koocher & O'Malley, 1981; Langeveld et al., 2004; Zeltzer, 1993). Together, the chronic uncertainty of life after cancer treatment (in terms of the unpredictability of disease course, potential fertility problems and other concerns regarding family planning) may impact the formation and maintenance of close, stable relationships.

While current understanding of factors associated with the development of healthy adult relationships suggests that the early stressors of diagnosis and treatment for childhood cancer are likely to have a long-term effect on survivors' dyadic relationships, the extant literature is still quite limited. To date, much of the empirical evidence focuses on child and adolescent survivors and fails to consider the transition to early adulthood, a developmental period thought to be particularly critical for



survivors' social maturation (Erikson, 1959, 1964). In the following sections, evidence of social difficulties among early survivors will be reviewed before turning to long-term effects experienced by young adult survivors.

#### **1.2.5. Social Problems among Child/Adolescent Survivors**

A number of studies examining social competence have been conducted among child and adolescent survivors of cancer (Mulhern et al., 1989; Newby, Brown, Pawletko, Gold, & Whitt, 2000; Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993; Olson, Boyle, Evans, & Zug, 1993; Pendley, Dahlquist, & Dreyer, 1997; Reiter-Purtill, Vannatta, Gerhardt, Correll, & Noll, 2003; Shelby, Nagle, Barnett-Queen, Quattlebaum, & Wuori, 1998; Sloper, Larcombe, & Charlton, 1994; Spirito et al., 1990), with the majority identifying impairment in some aspect of social functioning and/or interpersonal relationships. Teacher, parent, peer, and survivor self-report provide evidence of poorer social competence among survivors of childhood cancer (Mulhern et al., 1989; Noll et al., 1993; Olson et al., 1993; Pendley et al., 1997; Shelby et al., 1998; Sloper et al., 1994; Spirito et al., 1990). Teacher reports, for example, have indicated that survivors perform significantly worse than controls on measures of social competence (Olson et al., 1993), earn social competence scores below the published norms (Olson et al., 1993), and are rated as less popular with peers (Sloper et al., 1994). Parent report has identified survivors in a rural sample as four times more likely than controls to have social competence scores below the normal range (Olson et al., 1993). Similarly, in a separate school-aged sample, parent report identified 54% of survivors as deficient (based on population norms) on one or more of the Child Behavior Checklist's Social Competence scales, a level of impairment significantly greater than that found in the general population (Mulhern et al., 1989). Spirito and colleagues (1990) examined the social adjustment in a young cohort of survivors (5-12 years) and found that while teachers rated survivors as less likely than healthy classmates to argue with and be teased by others, the survivors themselves reported fewer friends of the same age and greater loneliness and isolation from

peers than did healthy controls. In a two-year longitudinal study, adolescents treated for cancer did not differ from controls on multiple measures of social acceptance yet were both self-identified and identified by peers as more socially isolated and withdrawn (Noll et al., 1993). Although this finding of impairment may be due to the high percentage of patients who had received cranial irradiation, the social seclusion of survivors is corroborated in a separate study, where adolescent cancer survivors reported less than half as many social activities as healthy controls (Pendley et al., 1997). These early difficulties of social isolation and impaired social competence may portend future interpersonal problems, as social skills and social opportunities are vital to the formation and maintenance of close relationships (Asher, Renshaw, & Geraci, 1980). Few studies, however, have examined the presence and nature of social sequelae beyond the adolescent years.

#### **1.2.6. Social Problems among Young Adult Survivors**

Survey research indicates that many survivors perceive their illness history as having an impact on their long-term social functioning. In a small sample of adult survivors, for example, 46% of survivors reported the belief that cancer had influenced the attainment of their social and family goals (Dolgin et al., 1999). Similarly, Meadows and colleagues (1989) indicated that 21% of their young adult survivor sample believed their disease impeded the ability to establish interpersonal relationships, with 38% reporting the belief that their illness history frightened people.

Multiple studies have reported lower rates of marriage (Langeveld et al., 2003; Novakovic, Fears, Horowitz, Tucker, & Wexler, 1997; Rauck, Green, Yasui, Mertens, & Robison, 1999) and cohabitation (Hays et al., 1992; Langeveld et al., 2003) among survivors compared to controls, as well as older ages at first marriage (Hays et al., 1992; Zeltzer, 1993) and romantic relationships of significantly shorter duration (Dolgin et al., 1999). These outcomes can be viewed as proxy measures of social impairment among survivors; they *imply* relationship problems that manifest as delayed attainment of certain social goals. In a recent study of adult long-term survivors of acute lymphocytic

leukemia (ALL) and Wilms' tumor and matched healthy controls (Hill, Kondryn, Mackie, McNally, & Eden, 2003), impairment was assessed more directly via standardized measures of interpersonal and social role performance, and survivors were found to report greater difficulties than controls in love/sex partnerships, friendships, and even non-specific social contacts (Hill et al., 2003). Indeed, ALL survivors' relative risk for a combination of deficits in both love/sex relationships and friendships was a striking 6.10 (Hill et al., 2003).

Only a few empirical studies have attempted to describe the nature of young adult dyadic relationships among survivors of childhood cancer. A small study conducted by Mackie and colleagues (2000) identified survivors as displaying *avoidant* functioning in romantic relationships; relative to control participants, their relationships were characterized by a lack of involvement or confiding. Combining quantitative and qualitative methods, Gray and colleagues (1992) found that compared to healthy controls, survivors thought more often about other people, preferred interacting with others, and reported more positive affect during these interactions. At the same time, however, survivors reported being significantly less satisfied with their partners and friends. Qualitative interviews revealed that in both friendships and romantic partnerships, survivors demonstrated heightened interpersonal sensitivity, cautiousness, and fear of personal disclosure. Together, these findings suggest a complicated orientation toward relationships—in which survivors appear more motivated to be with others and more valuing of others, while at the same time expressing caution in and dissatisfaction with their most significant relationships.

In sum, most studies of long-term survivors' close relationships have been limited to documenting the presence of certain relationship outcomes that may be markers of impairment (i.e. marriage rates, duration of relationships) or to making global statements regarding “problems” and “impairment” in close relationships without addressing or explaining the nature of these difficulties; as

such, many questions regarding the long-term social functioning of childhood cancer survivors remain unanswered. To address these gaps in knowledge, this study uses both quantitative and qualitative methods to conduct a more detailed exploration of close relationships among young adult survivors of childhood cancer and controls without a history of chronic illness. While this study focuses on self-reported relationship quality as the primary outcome, it also explores process variables that may act as mechanisms to outcome and investigates risk factors that may increase the likelihood of experiencing long-term social impairments.

To this end, Figure 1 presents a model of how certain social factors may be related to relationship satisfaction and thus, to relationship quality. Specifically, relationship satisfaction (the primary outcome of the proposed study), amount of conflict, and stability/duration are conceptualized as interrelated indicators of relationship quality. Expectations, intimacy, and fear of intimacy are conceptualized as process variables that may account for differences in these relationship quality components. The subsequent sections will describe briefly what is known about these variables (and the relationship among them) from the large literature on close relationships and will suggest how these relationship processes may be affected by the experience of childhood cancer.

### **1.3. Relationship Quality**

Relationship quality is a broad term that encompasses both subjective and objective assessment of how ‘good’ or ‘healthy’ or ‘satisfying’ a relationship is. While the existing literature on close relationships is quite extensive, there is little agreement among investigators as to what constitutes a high quality relationship. Assessment measures used most often in the field suggest that a high quality, close relationship is characterized by high ratings of satisfaction, low levels of conflict, and/ or high stability over time. Additional cognitive, affective, and behavioral components have been implicated as indicators of high quality, but an examination of

all these features is well beyond the scope of this investigation (for a review, see Clark & Reis, 1988). This study focused on relationship satisfaction as the primary outcome measure and indicator of relationship quality. Relationship conflict and duration were also assessed, along with a host of other variables like number of relationships in the past five years, level of distress in the face of a break-up, etc. Three constructs that may contribute to relationship quality through their effects on relationship satisfaction-- relationship expectations, intimacy, and fear of intimacy—were conceptualized as potential mediators.

### **1.3.1. Primary Outcome Measures**

#### **1.3.1.1. Relationship satisfaction**

Much of the literature examining relationship quality has focused on relationship satisfaction, which has been defined as a general and global construct that involves subjective evaluations of the relationship as meeting or exceeding an individual's set of internal standards (expectations) for a good relationship (Thibault & Kelley, 1959). Studies have identified satisfaction as a predictor of relationship (specifically marital) quality and, in general, have found that satisfied couples are well-adjusted (Aida & Falbo, 1991; Ptacek & Dodge, 1995).

#### **1.3.1.2. Relationship duration/stability**

High quality relationships are generally believed to last longer. Thibault and Kelley have acknowledged that usually people who are satisfied remain in their relationships (1959), that is, satisfaction is regarded as one of the determinants of commitment. When the costs of a relationship begin to outweigh the rewards (Rusbult, 1980) or we perceive the relationship to be unfair (Hatfield, Traupmann, Sprecher, Utne, & Hay, 1985), we are likely to consider terminating the relationship in favor of other social involvements that better meet our needs. Findings of less stable relationships among childhood cancer survivors (Dolgin et al., 1999), then, may be due to general dissatisfaction and/ or feelings that the costs involved in maintaining

the relationship (e.g., increased intimacy in the form of self-disclosure about cancer history, fertility status, etc.) outweigh the benefits. These possibilities, however, have not yet been studied in this potentially high risk population.

#### **1.3.1.3. Relationship conflict**

Conflict in close relationships is inevitable, and, according to some cognitive theories, occurs most frequently in relationships lacking in personal rewards or in those characterized by inequity (Hatfield et al., 1985; Van Yperen & Buunk, 1990). High conflict in a relationship increases the amount of felt distress by its partners and may contribute to lower levels of satisfaction and shorter duration/ less stability over time. Indeed, several self-report studies have found associations between a person's relational satisfaction and perception of one's own and partner's conflict behaviors and between constructive conflict management and the development of relational stability (Canary & Cupach, 1988; Rands, Levinger, & Mellinger, 1981; Spitzberg, Canary, & Cupach, 1994). Survivors who are less satisfied in their relationships may experience more conflict and, as a result of earlier social skill delays (e.g., Mulhern et al., 1989; Olson et al., 1993), may be less competent at managing it.

#### **1.3.2. Proposed Mediators of Relationship Quality**

A number of factors may affect an individual's satisfaction with his or her close relationships. Based on initial findings within the pediatric oncology literature, this study focuses on expectations, intimacy, and fear of intimacy. While these factors may also relate to relationship duration and conflict, literature to date has focused on their associations to satisfaction; these constructs, then, were assessed as potential mediators of satisfaction. Inclusion of mediators in this study adds to existing work, which has largely neglected consideration of process variables that might explain differences in social adjustment among childhood cancer survivors.

#### **1.3.2.1. Expectations**

Expectations about how partners and friends should act, about their own role in the relationship, about the availability/ accessibility of the friend or partner, and amount of support provided and received may, in fact, drive an individual's notion of satisfaction with his or her relationship. Thus, expectations may act as a mediator of the relationship between childhood disease status and later relationship satisfaction. Research outside the pediatric psychooncology field shows that what people expect to receive in their relationships affects how they evaluate them (McNulty & Karney, 2004). One line of research suggests that positive expectations may lead to positive outcomes (e.g., Baucom, Epstein, Rankin, & Burnett, 1996) and are necessary for developing and maintaining healthy relationship functioning. A separate line of research suggests, however, that positive expectations may be a source of relationship distress, as they leave people vulnerable to disappointment should those expectations fail to be met (e.g., Fletcher, Simpson, & Thomas, 2000; Thibault & Kelley, 1959). In the context of romantic relationships, couples are at increased risk when expectations are unreasonable, and partners who perceive that their ideal standards are not being met tend to be the least happy in their relationships (Fletcher et al., 2000). Indeed, endorsement of unrealistic beliefs about relationships has been related to lower levels of satisfaction (Eidelson & Epstein, 1982; Jones & Stanton, 1988).

Survivor reports of dissatisfaction in their important interpersonal relationships (Gray et al., 1992), then, may be an unfortunate consequence of the high expectations for relationships that were formed during the time of their initial illness and treatment. Interpersonal relationships may be unique during a time of potentially life-threatening illness, with friends and family being particularly (and perhaps exceedingly) attentive, compassionate, giving, and nonconfrontational. As a consequence, patients may form similar expectations for future close relationships, the reality of which may then be experienced as a let-down. In other words, survivors may maintain a different, more

stringent set of standards for relationships than their peers (i.e., may expect higher levels of emotional support, more time spent together, less conflict), thereby contributing to decreased satisfaction when the interpersonal relationships cannot measure up. As this interpretation has not yet been tested empirically, this study aims to replicate findings of decreased relationship satisfaction among survivors and evaluate expectations as a potential mediator of this outcome.

#### **1.3.2.2. Intimacy and fear of intimacy**

Sternberg (1997) defines intimacy as “feelings of closeness, connectedness, and bondedness in loving relationships”. A construct important to overall relationship satisfaction, intimacy is a multidimensional composite that includes love and affection, personal validation, trust, and self-disclosure (Hook, Gerstein, Detterich, & Gridley, 2003). It involves the expression of important self-relevant feelings and information to another that results in feelings of being cared for and of being validated (i.e. receiving confirmation of his/her world view and personal worth) (Clark & Reis, 1988; Reis & Shaver, 1988). Intimacy motivation, then, is viewed as a recurrent preference or readiness for experiences of close, warm, and communicative exchange with others (McAdams, 1984). Studies show that persons high in intimacy motivation, relative to those of less motivation, express greater trust and concern for friends, self-disclose more emotional, personal, and relational content, and have more frequent and more affectively positive interpersonal thoughts in daily interactions (McAdams & Constantian, 1983).

An important barrier to the growth of intimacy in close relationships may be the fear of intimacy itself (Hatfield, 1984). According to theorists, fear of intimacy refers to the inhibited capacity of an individual to exchange thoughts and feelings of personal significance with another individual who is highly valued (Descutner & Thelen, 1991). It is an anxiety-based construct with nervousness and apprehension as primary components. A person who fears intimacy, then,



would be anxious about sharing personal information about their past (e.g. cancer diagnosis), expressing intimate feelings or feelings of distress, entrusting their most private thoughts with another person, or taking the risk of being hurt in the context of a close relationship (Descutner & Thelen, 1991; Emmons & Colby, 1995; Prager, 1995,). Research indicates that fear of intimacy is positively correlated with self report measures of being difficult to get to know, of low satisfaction in dating relationships, uneasiness in developing close relationships, briefer relationships and increased levels of loneliness (Descutner & Thelen, 1991).

Negotiating intimacy appears to be a difficult process for some survivors of childhood cancer. Existing research has identified a complicated orientation toward intimacy in which survivors report heightened motivation toward intimacy (Gray et al., 1992) yet display cautiousness and avoidant functioning in the very relationships that may provide them with the intimacy they seek (Gray et al., 1992, Mackie et al., 2000). These findings, however, may not be as contradictory as they first seem, as intimacy theorists state that it is entirely possible for an individual to desire an intimate relationship while at the same time fear entering such a relationship (Thelen, Vander Wal, Muir Thomas, & Harmon, 2000). This complicated stance toward relationships deserves additional research, and as one dimension of relationship quality, intimacy among survivors is an important construct to consider.

#### **1.4. Methodological Improvements on Previous Studies**

The following study improves upon existing empirical work by providing a more focused exploration of the nature of dyadic relationships among survivors in a manner that is developmentally sensitive, incorporates both quantitative and qualitative methods, considers potential mediators of the relationship between childhood disease status and future relationship difficulties, and examines potential risk factors that may increase risk susceptibility. Before turning to the study's hypotheses, each of these methodological improvements will be addressed.

### **1.4.1. Developmental Considerations**

#### **1.4.1.1. Age at diagnosis and treatment**

A major limitation of the existing literature is a general failure to consider the child's developmental stage at the time of both diagnosis and follow-up assessment. Indeed, many investigators have expressed a need for research that is developmentally sensitive (Eiser, Hill, & Vance, 2000; Hill & Stuber, 1997; Joubert et al., 2001; Kazak et al., 1994; Stuber & Kazak, 1999; Woodgate, 1999). Because children face different challenges at different points in their development and because a child's developmental level affects how he/she experiences and interprets illness, it is likely that the long-term sequelae of childhood cancer will vary according to the developmental stage of the patient during treatment and during follow-up assessment. Thus far, studies assessing whether age at diagnosis moderates long-term psychological adjustment have reported inconsistent findings, with some indicating poorer adjustment for survivors diagnosed at younger ages (Eiser & Havermans, 1994) and others documenting poorer adjustment for those diagnosed at old ages, including more post-traumatic stress symptoms (Stuber, Christakis, Houskamp, & Kazak, 1996), poorer overall coping (Kupst et al., 1995), and of particular import to the present study, social quality of life (Zebrack & Chesler, 2002). Additional studies have found no relation between age of diagnosis and a variety of outcomes including self-esteem, problem behaviors (Rait et al., 1992), depression and somatic distress (Zebrack et al., 2002).

Studies examining the psychosocial late effects of treatment for childhood cancer typically utilize small samples that cover a wide-age range, and as a result, developmental differences in psychosocial adjustment have likely been obscured. At this time, then, it is not clear whether there is a critical period when the traumatic aspects of childhood cancer have more significant long term consequences (Stuber & Kazak, 1999). Attachment disturbances in infancy, school absences in middle childhood, and forced dependency in adolescence may represent different pathways to similar outcome

(impairment in close relationships), or diagnosis and treatment may be more detrimental to social development during a particular developmental stage. To clarify the role of development in the long-term outcome, this study explores age of diagnosis as a possible moderator of social adjustment among survivors.

#### **1.4.1.2. Age at follow-up**

A growing body of evidence suggests that survivors' age at follow-up assessment may be an important moderator of the experience of psychosocial distress. In general, younger survivors report few problems, or even better than normal adjustment (Greenberg, Kazak, & Meadows et al., 1989; Noll et al., 1993), while young adult and adult survivors endorse a wide range of psychological and social impairment (Erickson & Steiner, 1999; Hobbie et al., 2000; Zebrack et al., 2002; Zeltzer et al., 1997), including an increased risk of somatic complaints (Mulhern et al., 1989), more self-reported anxiety (Barakat et al., 1997), higher scores on the Global Severity Index of the SCL-90-R (Elkin et al., 1997), and a greater number of posttraumatic stress symptoms (Hobbie et al., 2000). These results suggest that there may be a developmental pattern to the emergence or reporting of psychological symptoms in childhood cancer survivors (Hobbie et al., 2000). Findings may reflect a worsening of symptoms over time, normal developmental patterns of symptom manifestation, the emergence of psychological "sleeper effects" (Wallerstein, 1989), or a developmentally-timed pattern to the reporting of psychological symptoms in childhood cancer survivors (Hobbie et al., 2000).

Some investigators have proposed that survivors of childhood cancer may be at increased risk for psychological distress as they face the challenges that accompany the transition to adulthood (Hobbie et al., 2000). New developmental tasks, like establishing functional independence, negotiating interpersonal intimacy, forming families, and making educational and employment decisions may induce reactions to their history of childhood cancer that differ from those of earlier developmental

periods (Hobbie et al., 2000). Perhaps during this phase of life, survivors most saliently incorporate their childhood cancer experience into their identity, face the potential late effects of treatment, and come to terms with their implications. Whether this integration causes new symptoms to emerge or brings about the recognition and acceptance of symptoms that have been underreported in the more protected adolescent years, the rate of report would still be expected to increase (Hobbie et al., 2000).

In light of evidence that symptom occurrence and reporting may increase during young adulthood and in line with Erikson's theory of psychosocial development that identifies intimacy vs. isolation as the primary task of young adulthood (Erikson, 1959), this developmental period may be a particularly crucial time to evaluate the long-term social effects of treatment for childhood cancer. As such, this study restricts age of follow-up assessment to emerging adulthood (ages 18-25); this sampling parameter ensures a more developmentally homogenous survivor group than previously studied and allows for a careful examination of social adjustment at what seems to be particularly critical developmental period.

#### **1.4.2. Consideration of Additional Risk Factors**

The general variability in adjustment to childhood cancer suggests wide individual differences among long-term survivors and indicates a need to identify risk and protective factors that can help explain different trajectories of outcome. Because the long-term social adjustment to childhood cancer may not be a simple linear relationship between disease status and outcome, this study examines age of diagnosis (discussed previously), trait anxiety, gender, and treatment intensity as risk factors for later relationship difficulties.

##### **1.4.2.1. Pre-existing psychopathology**

Intraindividual characteristics, particularly pre-existing psychopathology, may contribute to increased risk of maladjustment among survivors, as those with certain intrapersonal attributes may respond differently to similar environmental contexts. In other words, the stress and disruption caused

by diagnosis and treatment could exacerbate pre-existing psychosocial difficulties. Survivors with high trait anxiety, in particular, may be at increased risk for later relationship difficulties. According to Spielberger's theory (1972), trait anxiety denotes "relatively stable individual differences in anxiety proneness" and refers to a general tendency to respond with anxiety to perceived threats in the environment; it is distinguished from "state" anxiety-- a transitory emotional state that can fluctuate over time and vary in intensity and is characterized by subjective, consciously perceived feelings of tension and apprehension. High levels of pre-existing trait anxiety, in combination with the stress of diagnosis and treatment, may make survivors more hesitant to initiate social interactions and more concerned with how potential friends and partners perceive them. In addition, high trait anxiety may predispose survivors to perceive a variety of social situations and social cues as threatening and/or intimidating. Survivors high in trait anxiety, then, may be at highest risk for later impairments in close relationships.

#### **1.4.2.2. Gender**

Although not often a primary focus of long-term survivor research, several studies have evaluated whether psychosocial late effects of treatment for childhood cancer differ between the sexes. While the majority of findings support comparable levels of adjustment, not all findings are consistent. Female gender has been associated with increased risk of mood disturbance (Zeltzer et al., 1997), persistent post-traumatic stress symptoms (Stuber et al., 1997), and socialization difficulties (Butler, Rizzi, & Bandilla, 1999), but Sanger and colleagues (1991) found that boys exhibited significantly more problems than girls on 6 of the 12 clinical scales of the Personality Inventory of Children, including somatic concern, depression, delinquency, and anxiety.

Gender differences in close relationships are well-documented (see Winstead, Derlega, & Rose, 1997), with women's social involvements often considered more involved, more intimate, and of

longer duration (Barth & Kinder, 1988) than those of men. Across age groups, women are more likely to self-disclose private feelings and problems to others (Brehm, 1992; Fox, Gibbs, & Auerbach, 1985) while men prefer to talk about sports, politics and business. To date, no studies have examined whether gender influences social functioning among childhood cancer survivors, so it remains unknown whether men or women are at differential risk for impairments in close relationships.

#### **1.4.2.3. Treatment intensity**

As childhood cancer is not a single disease entity, treatment protocols differ substantially both across and within diagnoses. While some cancers may require surgery only, others may involve chemotherapy regimens of varying lengths and/or radiation therapy. A small number of studies in the survivorship literature have considered the contribution of treatment intensity to long-term psychosocial outcomes. Research suggests that more intense treatment histories (i.e., exposure to intensive chemotherapy, more frequent disease relapse) are associated with increased risk of later maladjustment (Elkin et al., 1997), including higher rates of PTSD (Hobbie et al., 2000), somatic distress and depressive symptomatology (Zebrack et al., 2002). Of particular import to the current study of close relationships, a recent study by Reiter-Purtill and colleagues (2003) reported that greater treatment intensity contributes to peer perceptions of survivors' having fewer best friends. As more intense treatment regimens may have more severe and lasting neuropsychological sequelae, require more school absences, and contribute to more profound functional impairment, treatment intensity is an important variable to consider when assessing any psychosocial outcome of childhood cancer survivors.

#### **1.4.3. Incorporation of Qualitative Methods**

The majority of the literature examining sequelae of childhood cancer has employed quantitative techniques. This approach enables the use of standardized and validated measures and permits the use of probability theory to test hypotheses and form statistical conclusions about

relationships between variables that can be generalized to the population. A quantitative approach is limited to a priori theoretical decisions about the critical components to be measured-- in this case, factors contributing to relationship satisfaction. Quantitative findings comparing survivors to population norms and matched control groups on such standardized measures of psychosocial adjustment have been inconsistent; group differences, however, have emerged when other methodologies, like interview data, are used, as they can highlight problems not captured by questionnaires (Gray et al., 1992). Consequently, several authors have noted that the measures employed by many of the existing studies may not be entirely appropriate for pediatric cancer populations (Eiser et al., 2000; Kazak, 1994; Stam et al. 2001). Generic instruments of psychosocial adjustment may be unable to assess specific problems resulting from treatment of childhood cancer and are potentially insensitive to more subtle adjustment difficulties. In light of these inadequacies, the incorporation of additional assessment techniques is critical. Gray and colleagues (1992) have suggested that qualitative, descriptive, within-group explorations of the impact of childhood cancer will be vital to a more complete understanding of the lives of survivors.

Qualitative methods are particularly well-suited to this study, whose purpose is to understand survivors' perceptions of their friendship and romantic relationships. Due to a notable lack of empirical findings and theoretically-driven hypotheses, there is a great deal of uncertainty surrounding this topic. As such, a basic interpretive and descriptive qualitative study focused on making sense of survivors' experiences is an appropriate supplement to traditional quantitative strategies—one that ultimately may generate specific hypotheses for future investigation.

### **1.5. Summary and Hypotheses**

In sum, social QoL is an important component of general well-being that has been somewhat neglected in the literature on young adult survivors of childhood cancer. Various aspects of the cancer

experience may contribute to future social maladjustment, including disruptions in normal attachment processes during infancy, frequent absences during the critical first years of formal schooling, and physical changes and compromised independence during adolescence. Much of the existing literature on social sequelae of cancer survivors has focused on cohorts of children and adolescents; the transition to young adulthood deserves further investigation. While the extant literature suggests that young adult survivors of childhood cancer may be at risk for difficulties in their close relationships, the nature and extent of these difficulties has yet to be explored fully. To that end, this study focuses primarily on self-reported relationship satisfaction as an indicator of relationship quality and tests the following hypotheses:

1. Compared to peers without a history of chronic illness, young adult survivors of childhood cancer will report lower relationship satisfaction and higher conflict in their close relationships (both friendship and romantic). In addition, survivors' will report having fewer and shorter romantic relationships than controls.
2. Survivors will report higher expectations for their close relationships, as well as lower levels of and a greater fear of intimacy in those relationships. These constructs (separately) will mediate the relationship between childhood disease status and young adult relationship satisfaction (see Figure 2).
3. Trait anxiety will moderate the relationship between childhood cancer status and later relationship satisfaction such that *survivors* with high levels of trait anxiety will report the lowest levels of satisfaction.

In addition, exploratory analyses will be conducted to evaluate the role of gender, age of diagnosis, and treatment intensity in the prediction of later relationship satisfaction. Dummy



coding procedures will permit comparison of controls and survivors diagnosed at different ages and exposed to different treatment intensities. Within-group analyses will be conducted to explore multiple risk factors (and the interactions among them) in the survivor group that may contribute to future relationship difficulties. Finally, a basic interpretative qualitative study will gather adjustment-specific information not captured by standard measures and to evaluate how survivors themselves perceive their close interpersonal relationships.

## **2. Method**

### **2.1. Participants**

#### **2.1.1. Survivors**

Sixty young adult survivors of childhood cancer were recruited through Children's Hospital of Pittsburgh (CHP). CHP's computer database identified a pool of 732 childhood cancer survivors currently between the ages of 18 and 25. Patients were excluded from study participation if they were less than two-years off treatment or if their primary cancer involved the central nervous system (i.e., brain tumor). These criteria narrowed the number of eligible participants to 603. An initial contact letter and study consent form was sent to eligible patients from the Chief of Pediatric Hematology/Oncology, Dr. Kim Ritchey, describing the goals and importance of the proposed study, the nature of requested participation, and amount of compensation. Interested participants were asked to contact the principal investigator with current contact information or to call the study office directly. This initial mailing resulted in the recruitment of 52 eligible survivors. Six months after the initial contact letter, a follow-up mailing was sent to the 551 survivors who had not responded. This second letter resulted in the recruitment of an additional 8 survivors.

Illness variables for the 60 participating survivors are found in Table 1. The majority of survivors were diagnosed with ALL (36.6%), followed by Hodgkin's Lymphoma (10.0%) and NonHodgkin's Lymphoma (10.0%). Age of diagnosis ranged from 1 to 17, with a mean of 8.06. Average time off treatment was 12.73 years, with a range from 3 to 22 years.

#### **2.1.2. Controls**

60 demographically similar, healthy control participants were recruited through a combination of two strategies. Exclusionary criteria included any past or current chronic illnesses (i.e., conditions lasting for an extended period of time that need to be managed on a long-term basis and involve some form of impairment in functioning), including cancers, sickle

cell anemia, diabetes, and cystic fibrosis. Initially, survivor participants were asked to approach one or more of their same-sex peers between the ages of 18-25 about the possibility of study participation. Interested peers contacted the principal investigator via phone or email for more information. This word-of-mouth strategy resulted in 23 successful referrals. To recruit a large enough control sample for analyses, then, a second strategy was employed. Additional controls were recruited via the University of Pittsburgh's Introduction to Psychology Subject Pool, coordinated by Dr. Richard Moreland. A short bulletin describing the study and nature of requested participation was posted on the University's research webpage along with contact information for the principal investigator. After completion of the online surveys, these subject pool participants were awarded 1 research credit hour as compensation for their time. This method resulted in the recruitment of 37 additional control participants.

Referral controls and subject pool controls were compared on a number of demographic and relationship variables. Subject pool controls were significantly younger than referral controls, ( $M = 21.63$  referrals,  $M = 19.10$  for subject pool controls,  $t = 7.01$ ,  $df = 58$ ,  $p < .01$ ) but did not differ on any other variable.

### **2.1.3. Demographics**

Sample demographics are included in Table 2. Survivor and control groups did not differ on key demographic variables such as gender, marital status, education, and parental education. The survivor group, however, was significantly older than the control group ( $M = 21.61$  for survivors,  $M = 20.05$ ,  $t = -4.33$ ,  $df = 118$   $p < .01$ ), a likely consequence of having to rely on a university's Introductory Psychology Subject Pool as a secondary recruitment source, as individuals in this pool were largely college freshman.

## **2.2. Procedure**

### **2.2.1. Initial Contact**

During the initial contact, interested participants completed a brief screening intake to ensure eligibility. For survivors and their referred peers, informed consent was conducted over the phone, and those who agreed to participate were asked to sign and return the hard copy of the consent form that was included with the initial contact letter (if they had not already done so). For subject pool controls, the screening and consent process took place face-to-face in the study office. After consent, all participants were told how to access the study website and were given their individualized log-in id and password. They were encouraged to contact the study office if they had any questions about accessing and/or completing the on-line measures or if they experienced any general problems with the website. After the survivor participants and the referred peers completed the on-line measures and sent their responses to the study server, they received \$25.00 compensation. Subject pool controls received 1 research credit hour. If a participant did not have internet access, hard copies of the study measures were sent to their homes, along with a postage-paid envelope for easy return. Only 1 participant in the entire sample chose this option.

### **2.2.2. Internet-based Assessment**

The nature of the proposed study made data collection via the World Wide Web an appealing alternative to assessments conducted in the study office. The survivor sample of interest was spread over a wide geographic area, as CHP has a large catchment area, serving the needs of several states (OH, PA, WVA, MD). It was not feasible, then, to expect participants to travel long distances to take part in a fairly brief, questionnaire-based study. While some participants still lived at home with their parents, many were away at college, living out of the house, married, and/or relocated. The use of the Web allowed for data collection regardless of current location, reducing the burden on potential participants (coordinating an interview time,

traveling to the study office, etc.). Participants could come on-line at a time that was convenient for them from computers at home, school, or work. In addition, given that participants were responding to questions regarding the nature of their interpersonal relationships, there may have been added benefit to the anonymity of the Web.

Each participant received a unique username and password to logon to the web site, which was powered by Microsoft Windows SharePoint Services. All Internet traffic to the web site was encrypted using 128-bit SSL encryption-- the same encryption used for credit card purchases at Amazon.com. Once authenticated to the web site, participants had the opportunity to respond to each measure exactly one time. After completion of the measures, participants were able to review their own answers but were not be able to modify them or to view the answers of other participants. Data was stored in a Microsoft SQL Server database and was accessible only by the principal investigator and the systems administrator.

## **2.3. Quantitative Measures**

### **2.3.1. Demographics**

A standard demographic form collected data on participants' age, gender, race, highest level of education, current marital status, parental education level, and parent marital status.

### **2.3.2. Treatment Intensity**

Ratings of treatment intensity (based on the work of Hobbie et al., 2000) were created from medical data collected via chart review. The principal investigator extracted relevant medical variables from survivors' medical records, including initial diagnosis, site of pathology, age of diagnosis, Children's Oncology Group (COG) treatment protocol number, length of treatment, and experience of relapse (yes/no). Treatment-specific information was also gathered, i.e., whether the patient had surgery, chemotherapy, radiation, and/or a bone marrow transplant. For patients treated with chemotherapy, specific chemotherapy agents were recorded along with

number of courses administered. Site and total dosage of radiation were recorded where relevant. A consulting pediatric hematologist/oncologist then used these variables to rate each survivors' treatment intensity. The Treatment Intensity rating categories (Hobbie et al., 2000) were as follows:

1 (mild): surgery only and/or 6 months of chemotherapy for low-risk cancers according to COG treatment protocol; mostly outpatient therapy

2 (moderate): treatment for average-risk cancers according to COG treatment protocol

3 (severe): Bone marrow transplant, high-risk COG protocols; high doses of radiation; mostly inpatient therapy.

Treatment intensity data was available for 55 of the 60 survivor participants, as 5 charts could not be located by hospital staff or contained insufficient information. Using the above classification system, most survivors received ratings of "moderate" or "severe" treatment intensity ( $n = 26$  and  $n = 24$ , respectively). Only 9.3% of participants ( $n = 5$ ) qualified for the "mild" rating.

### **2.3.3. Relationship History**

An adaptation of The Dating/Romantic Relationships Measure (Bagwell, 1996) documented participants' relationship history over the past five years. This measure requires respondents to list and evaluate their current and past significant relationships in terms of type of relationship (i.e., marriage, living together, dating only each other, dating each other and other people), duration (yrs: months), and average amount of conflict (scale of 1-5, ranging from 'none' to 'severe'). For each relationship, respondents are also asked to indicate who was responsible for the "break-up" and how distressed they were at the dissolution of the relationship (scale of 1 to 5, ranging from 'not at all' to 'extremely'). A single question was added to this questionnaire, asking participants to indicate which relationship in the last five years they

considered to be the most significant. The indicated relationship, then, became the reference point for assessment of romantic relationships in subsequent measures.

#### **2.3.4. Relationship Satisfaction**

Relationship satisfaction was assessed with two brief inventories, the Relationship Assessment Scale (Hendrick, 1988) and the Quality of Marriage Index (Norton, 1983). As there are no well-validated measures of adult *friendship* relationship quality, the measures of marriage/dating relationships described below were adapted for use in the proposed study. Language was adjusted such that words like “partner” and “spouse” were replaced with “friend” and “marriage” with “relationship”. Making linguistic modifications of this sort is a widely used strategy in the extant literature (Clark, personal communication) and allowed for the use of comparable measures across relationship-type. All participants, then, responded to each measure twice: once for their most significant romantic relationship in the past five years (regardless of whether or not they were currently involved with someone) and once for a close, same-sex friendship.

##### **2.3.4.1. The Relationship Assessment Scale (RAS)**

The Relationship Assessment Scale (Hendrick, 1988) is a seven-item, five-point Likert scale measure of global relationship satisfaction among not just married partners but anyone in an intimate relationship, including dating, cohabitating, and engaged couples. The RAS provides a concise picture of the respondent’s perceptions of relationships and includes information about conflict and expectations. It has been said to provide a more parsimonious measure of relationship satisfaction than the Dyadic Adjustment Scale (Spanier, 1976) and has been found to be just as sensitive at discriminating between dating couples who stayed together and those who broke up several months later (Hendrick, 1988). Because the RAS is not limited to marriage, it can be used to assess a variety of relationships. The sum of seven items yields a total score (range 7-35) for interpretation, with higher scores indicating greater relationship satisfaction.

#### **2.3.4.2. Quality of Marriage Index (QMI)**

The QMI (Norton, 1983) is a six item inventory that assesses marital quality using broadly worded global terms (e.g. “We have a good marriage). The respondent indicates the degree of agreement with each of five items on a scale ranging from 1 (very strong disagreement) to 7 (very strong agreement) and with one item on a scale ranging from 1 (very strong disagreement) to 10 (very strong agreement). This scale yields scores ranging from 6 to 45, with higher scores reflecting more satisfaction with the relationship.

As these two measures were very highly correlated for both romantic and friendship relationships ( $r = .89$  and  $r = .80$ , respectively), the RAS was chosen as the outcome measure of relationship satisfaction, as this measure had been previously validated on nonmarried couples.

#### **2.3.5. Proposed Mediators**

##### **2.3.5.1. Expectations**

Participants were asked to report their expectations for their partners using a nine-item measure developed by McNulty and Karney (2004) for their study of expectations in the early years of marriage. This measure asks participants to rate their agreement with a series of statements (e.g. “My partner will agree with me about important things”; “My partner will always take time for me when I need him/her”) on a scale from 1 (strongly disagree) to 7 (strongly agree). Items are summed to form a single index, ranging from 7-63, with higher scores indicating more positive expectations/ a tendency for participant to have more positive expectations for their partner/ friend’s behavior.

##### **2.3.5.2. Intimacy**

The Miller Social Intimacy Scale (Miller & Lefcourt, 1982) is an empirically driven, 17-item, affective and cognitive measure of intimacy developed with college students and married couples in therapy. The MSIS was designed to assess the frequency of certain intimate behaviors



(6 items) and the intensity of affect experienced (11 items) within the context of close relationships-- either a marriage or a friendship. All items are rated on a 10-point scale and summed to yield the maximum level of intimacy experienced in the given relationship; higher scores on the measure indicate a greater degree of intimacy. The MSIS has a two-month test-retest reliability of .96. It has adequate convergent validity with several other intimacy measures and possesses satisfactory discriminant validity and excellent reliability (Hook et al., 2003; Miller & Lefcourt, 1982).

#### **2.3.5.3. Fear of intimacy**

The Fear of Intimacy Scale (Descutner & Thelen, 1991) is a 35-item, theory driven instrument designed to assess the fear of intimacy in a close relationship and *at the prospect* of a close relationship and therefore allows for assessment regardless of whether or not a respondent is presently involved in a relationship. The FIS asks partners to rate how they would feel sharing personal things about the past, entrusting their most private thoughts with another person, being impulsive and taking the risk of being hurt in the context of a close relationship (Prager, 1995). Data indicate that the FIS is a valid and reliable measure of individual's anxiety about close, dating relationships. It has high test-retest reliability (.89 at 1 month) and acceptable construct validity supported by factor analysis and comparison with other measures. The dominance of one primary factor provides support for the scale as a unidimensional measure. Convergent and discriminate validity were established with a number of related self-report measures (Descutner & Thelen, 1991).

Items are rated on a 5-point Likert-type scale ranging from 1 (not at all characteristic of me) to 5 (extremely characteristic of me). Approximately one half of the items are reversed scored to mitigate response bias. Higher scores are indicative of greater fears.

### **2.3.6. Proposed Moderators**

#### **2.3.6.1. Gender**

Participants will indicate their gender on the initial demographic questionnaire.

#### **2.3.6.2. Trait anxiety**

The State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983) is frequently used in research world-wide. For the purposes of this study, only the 20 items assessing *trait* anxiety were administered. Using a four-point Likert scale ranging from “almost never” to “almost always”, statements that assess how individuals feel “generally” (e.g. “I am a steady person”; “I lack self-confidence”). Interpretation is easy, as high scores indicate more anxiety. Both percentile ranks and standard scores are available for a variety of male and female samples. The STAI has superior internal consistency; alpha coefficient for the trait anxiety scale is 0.90. Test-retest stability is also relatively high for the trait anxiety scale with median stability coefficients as high as 0.77 (Spielberger, Sydeman, Owen, & Marsh, 1999).

## **2.4. Qualitative Interview**

After completion of the web-based measures, female survivors ( $n = 40$ ) were recontacted and asked to participate in a follow-up telephone interview based on a semi-structured format. The study’s principal investigator served as the interviewer for all participants. During the interview, respondents were asked a series of focused, open-ended questions (see Appendix A) about the nature of their romantic and friendship relationships. Only at the conclusion of the interview did the interviewer ask participants to reflect specifically on how they feel their early experience with cancer may have affected their friendships and romantic relationships. Throughout the course of the interviews, the interviewer probed for additional information as necessary, through the use of standard prompts like “Could you tell me more about that?” and “What was that like for you?” Follow-up questions were not prepared ahead of time, but rather

determined by the content of participants' answers; they focused on pursuing clarification of key terms, following-up incomplete answers or inconsistencies, asking for concrete examples, and questioning generalizations. All phone interviews were digitally recorded, and prior to content-based analyses, they were transcribed verbatim and checked for accuracy by a graduate level research assistant.

## **2.5. Data Analysis**

### **2.5.1. Quantitative Analysis**

Multivariate regression was employed as the general analytic strategy. Prior to all analyses, variables were tested to assess whether they met the assumptions of regression. Distribution of variables was inspected graphically (via frequency distributions) and statistically (via skew and kurtosis values). On both accounts, all variables appeared to be normally distributed and therefore did not require transformation. Examination of residual plots (plots of the standardized residuals as a function of standardized predicted values) indicated that the assumptions of linearity and homoscedasticity were met. Reliability estimates (Cronbach alphas) were all acceptable ( $>.7$ ).

To reduce nonessential multicollinearity, continuous predictor variables in all regression analyses were centered by subtracting the group mean from individual scores. Variance inflation factors and tolerance values indicated no problems with multicollinearity among predictors. To evaluate the reliability and generalizability of the results, residual diagnostics (specifically DFFITS and DFBETAS) were examined to determine whether particular cases were influencing the overall regression equation (FITS) and, if so, on what variable(s) they were manifesting themselves (BETAS) (Fox, 1991). One outlier in only two models was identified as compromising the stability of the model, and as a result was removed from the analyses.

Hierarchical regression was used to test for group differences between survivor and control groups on all romantic and friendship relationship variables, as well as mediators and moderators of the relationship between childhood illness status and relationship outcomes<sup>1</sup>. Categorical outcomes (e.g., currently in a relationship) were assessed via logistic regression. Current age was included as a covariate in all analyses, and correlation matrices between predictor and outcome variables were included to facilitate interpretation of results. Significant interactions (and trends) were probed using the methods of Aiken and West (1991), which involve plotting the interaction via simple slopes and post hoc statistical testing.

### **2.5.2. Qualitative Analysis**

After transcription, the interviews were assessed via qualitative content-based analysis as described by Auerbach and Silverstein (2003). Transcripts were first read, and re-read, in their entirety by the principal investigator to gain a holistic sense of each survivor's experience. Text was then reduced to manageable proportions by reading through the text with the research concerns in mind. Relevant text that was related to these concerns was retained and coded for repeating ideas (i.e., those expressed in relevant text by two or more participants) that shed light on the research issues. Themes, or implicit topics that organize a group of repeating ideas, were extracted and organized into a summary of what was learned about survivors' close relationships. This summary employed participants' own words as much as possible but also incorporated the researcher's interpretations.

---

<sup>1</sup> All analyses were run both with and without the Introductory Psychology Subject Pool controls (who were significantly younger than both the survivors and their referred peers); as findings were not appreciably different, they were retained in the control sample and included in the presentation of results.

### **3. Results**

Results from the quantitative analyses are presented first, beginning with an examination of hypotheses related to romantic relationships before turning to an examination of friendships. The subsequent section provides results of the exploratory analyses; between-group findings are presented first, followed by within-group findings. In the final section, qualitative findings from the interviews are discussed.

#### **3.1. Quantitative Results**

Table 3 provides sample descriptive statistics for the relationship measures.

##### **3.1.1. Romantic Relationships**

###### **3.1.1.1. Group differences on romantic relationship variables**

Table 4 shows percentages and means for the romantic relationship variables. Cohen's  $d$ s (Cohen, 1988) and Odds ratios are reported as indicators of effect size for continuous and dichotomous outcomes, respectively. No group differences were found for the primary outcome measures of relationship satisfaction, average conflict, or average duration. A significant difference was found for number of relationships in the last five years, such that survivors reported being involved in fewer relationships than controls ( $M = 1.77$  for survivors;  $M = 2.29$  for controls,  $\beta = -.24$ ,  $p = .01$ ). This difference was of moderate effect size ( $d = .45$ ). A moderate-to-large effect ( $d = .60$ ) was found for average level of distress reported at the end of a relationship, with survivors being more distressed ( $M = 3.41$  for survivors;  $M = 2.79$  for controls,  $\beta = .25$ ,  $p = .03$ ) than controls. At the time of assessment, significantly more controls than survivors were currently involved in a relationship (70.8% vs. 52.6%, Wald  $\chi^2 = 6.72$ ,  $df = 1$ ,  $p = .01$ ). No differences were found between survivors and controls for expectations, intimacy, or fear of intimacy.

### **3.1.1.2. Moderation of relationship between childhood disease status and romantic relationship satisfaction**

Zero-order correlations among predictor and outcome variables are presented in Table 5 to facilitate interpretation of results. Highly significant correlations were reported among all relationship measures<sup>2</sup>.

As proposed, trait anxiety and gender were examined as possible moderators of the relationship between childhood disease status and romantic relationship satisfaction. For this purpose, two separate regression models were tested. In each case, current age and the potential moderator (anxiety or gender) were entered in Step 1. Childhood illness group was entered in Step 2, followed by the interaction of illness group and the moderator in Step 3. The interaction term was not significant in either model, indicating that neither trait anxiety nor gender moderated the relationship between childhood illness status and romantic relationship satisfaction ( $\beta = -.14, p = .30$ ;  $\beta = .18, p = .55$ , respectively; Table 6).

Additional exploratory analyses examined whether these (anxiety and gender) and other factors (i.e., current age) moderated the relationship between childhood illness group and the other relationship outcomes (i.e., expectations, intimacy, and fear of intimacy). Only one significant interaction was found. With fear of intimacy in romantic relationships as the dependent variable, there was a significant childhood illness group by current age interaction ( $\beta = .31, p = .03$ ), such that older controls reported less fear of intimacy than survivors ( $\beta = -.26, p = .07$ ; see Figure 3).

---

<sup>2</sup> A post hoc principal components analysis confirmed that satisfaction, expectations, and intimacy all loaded on the same factor (.90, .87, .85, respectively).

### **3.1.1.3. Mediation of relationship between childhood disease status and romantic relationship satisfaction**

An assumption of mediation is that three paths exist (see Figure 2): 1) between the independent variable and the dependent variable prior to controlling for the variance accounted for by the mediator (path c); 2) between the independent variable and the mediator (path a); 3) between the mediator and the dependent variable (path b) (Baron & Kenny, 1986). A second assumption is that the magnitude of the path c effect is substantially diminished after accounting for the effects of the mediator (Baron & Kenny, 1986). Because no main effects of relationship satisfaction were found (path c), mediation analyses could not be conducted.

### **3.1.2. Friendship Relationships**

#### **3.1.2.1. Group differences on friendship relationship variables**

No group differences were found between survivors and controls on satisfaction, expectations, intimacy, or fear of intimacy in friendships. Results are shown in Table 7.

#### **3.1.2.2. Moderation of relationship between childhood disease status and friendship relationship satisfaction**

Zero-order correlations among predictor and outcome variables are presented in Table 8 to facilitate interpretation of results. Once again, highly significant correlations were reported among all friendship relationship measures.

In order to test trait anxiety and gender as potential moderators of the relationship between childhood disease status and friendship relationship satisfaction, two separate regression analyses were conducted. The moderator (anxiety or gender) and current age were entered in Step 1, followed by childhood illness group in Step 2, and the interaction of childhood illness group and the moderator in Step 3. A trend was found for the interaction of childhood illness status and trait anxiety ( $\beta = -.27$ ,  $p = .06$ ; see Table 9), such that survivors with high levels of

trait anxiety reported lower relationship satisfaction ( $\beta = -.27$ ,  $p = .03$ ; see Figure 4). The interaction of childhood illness status and gender was nonsignificant ( $\beta = .07$ ,  $p = .95$ ; Table 9).

### **3.1.2.3. Mediation of relationship between childhood disease status and friendship relationship satisfaction**

As there was no group effect of friendship relationship satisfaction, mediation analyses could not be conducted.

### **3.1.3. Exploratory Analyses**

#### **3.1.3.1. Age of diagnosis**

To investigate the role of age of diagnosis on outcome, the sample was divided into 4 groups: controls ( $n = 60$ ), survivors diagnosed between the ages of 0 and 5 ( $n = 23$ ), survivors diagnosed between the ages of 6 and 11 ( $n = 17$ ), and survivors diagnosed at 12 or older ( $n = 20$ ). Binary dummy codes were assigned to allow for comparison between groups, and once again, multiple regression was used to test for group differences in all relationship variables. Results indicate that survivors diagnosed in adolescence had significantly fewer relationships in the last five years than controls ( $\beta = -2.44$ ,  $p = .02$ , see Figure 5). While no other differences reached conventional levels of statistical significance, a general pattern emerged such that relative to controls and survivors diagnosed at both earlier age groups, survivors who were diagnosed in adolescence (12 and over) had more difficulties in romantic relationships. Specifically, they reported less relationship satisfaction in both romantic and friendship relationships, greater distress at the end of romantic relationships, and lower levels of intimacy with both their friends and partners. This pattern should not be dismissed, as small sample size of the survivor age groups likely limited power to detect significant effects.



### **3.1.3.2. Treatment intensity**

To investigate the role of survivor treatment intensity on outcome, the sample was again divided into groups and binary dummy codes were assigned to allow for comparison between controls ( $n = 60$ ), survivors with mild treatment intensity ( $n = 5$ ), survivors with moderate treatment intensity ( $n = 26$ ), and survivors with severe treatment intensity ( $n = 24$ ). Results indicate that survivors in the high intensity group had significantly fewer relationships in the last five years than controls ( $\beta = -.19$ ,  $p = .05$ , see Figure 6). Trends were found for survivors in the high intensity group to report less relationship satisfaction in their romantic relationships ( $\beta = -.17$ ,  $p = .10$ ; see Figure 7) and friendships ( $\beta = -.17$ ,  $p = .10$ ; see Figure 8) and more distress at the end of a romantic relationship ( $\beta = .21$ ,  $p = .07$ ; see Figure 9) than controls. There were also marginal differences between the high intensity group and the low intensity group on these same variables ( $p = .07$  for all).

### **3.1.3.3. Within-group analyses of romantic relationships**

A number of within-group analyses were conducted to investigate factors contributing to relationship assessment in the survivor group. Female survivors had significantly more relationships in the last five years than male survivors ( $t = 2.70$ ,  $df = 54$ ,  $p = .01$ ). There was a trend for males to report higher levels of trait anxiety ( $t = -1.86$ ,  $df = 55$ ,  $p = .06$ ). Significant interactions were found for age of diagnosis and trait anxiety such that an older age of diagnosis and high trait anxiety predicted low levels of relationship satisfaction ( $\beta = -.49$ ,  $p = .05$ ; ) and high levels of fear of intimacy ( $\beta = .31$ ,  $p = .10$ ; see Figures 10 and 11). Gender by trait anxiety interactions approached significance for the prediction of both relationship satisfaction ( $\beta = -.83$ ,  $p = .06$ ) and average amount of conflict across relationships ( $\beta = .77$ ,  $p = .10$ ). Specifically, males with high levels of trait anxiety reported the lowest levels of relationship satisfaction ( $\beta = -.40$ ,  $p = .11$ ) and highest level of conflict ( $\beta = .52$ ,  $p = .11$ ). Females with high trait anxiety, on

the other hand, reported the lowest levels of conflict ( $\beta = -.68$ ,  $p = .15$ ; see Figures 12 and 13). A main effect was found among treatment intensity rating groups, such that higher treatment intensity was related to lower relationship satisfaction ( $\beta = -.34$ ,  $p = .02$ ). There was also a trend for higher treatment intensity to be related to higher levels of conflict in relationships ( $\beta = .25$ ,  $p = .10$ ). A significant interaction was found between treatment intensity and trait anxiety in the prediction of intimacy ( $\beta = -1.20$ ,  $p = .04$ ), such that survivors with high trait anxiety who experienced more severe treatment reported lower levels of intimacy in their romantic relationship ( $\beta = -.38$ ,  $p = .07$ ; see Figure 14). Similarly, a trend was found for the interaction of treatment intensity and trait anxiety in the prediction of romantic relationship satisfaction ( $\beta = -.87$ ,  $p = .09$ ), such that higher trait anxiety and more severe treatment predicted lowest levels of relationship satisfaction ( $\beta = -.55$ ,  $p = .01$ ; see Figure 15).

In general, then, the pattern of significant interactions within the survivor sample identifies high trait anxiety, male gender, more severe treatment intensity, and an older age of diagnosis as significant risk factors for a host of difficulties in romantic relationships, including fewer number of relationships, lower levels of relationship satisfaction, greater fear of intimacy, lower levels of intimacy, and greater levels of conflict.

#### **3.1.3.4. Within-group analyses of friendships**

Within-group analyses were conducted for the friendship data just as they were for romantic relationships, but fewer significant findings emerged. An older age of diagnosis was significantly related to less reported intimacy with a close friend ( $\beta = -.29$ ,  $p = .03$ ). Females reported greater intimacy with their close friend ( $t = -2.82$ ,  $df = 54$ ,  $p = .01$ ) while males reported significantly greater fear of intimacy in friendships ( $t = -2.08$ ,  $df = 54$ ,  $p = .04$ ). There was a trend indicating a positive association between trait anxiety and lower relationship satisfaction ( $\beta$

= -.25,  $p = .06$ ). Within the survivor sample, there were no significant interactions between age of diagnosis, gender, trait anxiety, or treatment intensity for any of the friendship outcomes.

### **3.2. Qualitative Interview Findings**

A total of 20 female survivors of childhood cancer agreed to participate in the qualitative interview portion of the study. As 2 survivors reconsidered and reported being too busy, 18 actually completed the interview. Average interview time was 35 minutes. Basic demographic and illness variables are provided for this subsample in Table 10. In general, current age ranged from 19 to 25, age of diagnosis ranged from 2 to 15 (mean = 7.4 yrs old), and number of relationships in the past five years ranged from 1 to 4. Two thirds of the interview participants were currently in relationships. One survivor was married, one divorced, and the rest single. Interview participants ( $n = 18$ ) were compared with female nonparticipants ( $n = 22$ ) on a number of demographic and relationship variables; no group differences were found. There was a trend ( $p = .06$ ), however, for interviewed females to have higher trait anxiety than those who were not interviewed.

Overall, it was apparent that the interviewed survivors viewed their past illness as a life-changing experience that shaped who they had become and how they viewed the world. It was striking how eloquent and thoughtful the responses to cancer-specific inquiries were, suggesting that the survivors had given these issues a great deal of forethought and that they had processed the experience and incorporated it into their self-image and worldview long before the scheduled interview. Only two survivors described the impact of their illness as wholly negative and persistent; the majority offered a generally positive worldview in spite of prominent relationship-specific difficulties. In this way, it appears that having childhood cancer both enriched *and*

complicated their lives, as it was associated with new appreciations and opportunities and with new fears and challenges.

To that end, themes and subthemes that recurred in at least three interviews are discussed below. Illustrative excerpts from the transcripts are included, with additional verbatim text available in Appendix B.

### **3.2.1. Maturity and Perspective**

Interviewed survivors reported feeling different than their same-aged peers in a number of ways, but they most often identified themselves as feeling more mature and as having a vastly different life perspective. These differences appear to act as double edged swords in the development and maintenance of close interpersonal relationships. In the context of friendships, for example, survivors spoke of having gained a heightened sense of compassion for others, while at the same time having difficulty relating to the problems, concerns, and preoccupations of same-aged individuals. In romantic relationships, survivors seem to struggle to find a mature, like-minded mate, yet once involved, their ‘don’t sweat the small stuff’ attitude may help to reduce the amount of conflict they experience within that relationship.

During the time of their treatment, patients are removed from the typical world of childhood/adolescence and thrust into an environment that requires them to confront their own mortality, cope with painful medical procedures, interact with an endless stream of adult medical personnel, and deal with a reality few children ever have to face-- circumstances that ultimately generate emotional maturity. As one interviewed survivor recalls, “you have no choice, you’re forced to grow up quickly,” and as part of growing up quickly, patients seem to develop increased emotional maturity and a new perspective on life. Several survivors spoke of how their priorities changed, how they came to value their health and their families above most other things and to view life as precious. They spoke of gaining independence, a sense of confidence

in themselves and their decisions, the capacity to adapt to change, a greater appreciation of their parents, and a strong commitment to helping others. One survivor explained, “You come out of it and you feel lucky; it changes you, makes you definitely have a different outlook on life cause you realize life is so short and anything can happen.” These reports are in line with previous research that a portion of childhood cancer survivors report positive growth as a function of their illness experience, specifically having a sense of purpose in life, a hopeful life attitude, and a mature self-image (Eiser & Havermans, 1994; Maggiolini et al., 2000; Zebrack & Chesler, 2002). Instead of a delayed maturation that might be expected as a result of missed social and academic opportunities during the time of diagnosis and treatment, survivors—almost without exception-- report perceptions of *accelerated* maturation as a consequence of their experiences.

#### **3.2.1.1. Influence on friendships**

Although most survivors identified their new maturity and life perspective as positive consequences of childhood cancer, they also recognized them as barriers to forming close relationships with individuals of the same chronological age. While most survivors described being at total ease around adults, over half the interviewees spoke of how their cancer experiences made it difficult to relate to and fit in with their peers at that time of treatment, immediately after treatment end, and, in some cases, many years later. This difficulty may be related to survivors’ self-reported unwillingness to “waste time worrying about stupid things.” After coping with the demands of diagnosis and treatment, these survivors seemed to have a lower tolerance for typical adolescent and young adult concerns of appearance, popularity, casual dating, partying, etc., and even reported feeling like they had to feign interest in these things to fit in with their peers. Recalling her return to high school at the end of her treatment, for example, one survivor admitted, “I never really cared to be in a clique or anything cause it just

seemed so superficial compared to the things I had gone through. Stuff like that never mattered to me.” Another survivor put it quite simply, “The things that have happened have opened my eyes and made me realize that there’s more to life.” A 23 year old survivor of ALL explained,

“I know for a fact that when I was 15 or 16 and returned back to school, I felt like I was decades more mature than the rest of the kids at school and I feel like that’s still kinda a factor today. Like I feel like I have wisdom or maturity far beyond how old I am and sometimes its hard for me to click with other people my age. They’re still talking about having a bad hair day and I know what its like to not have hair.”

For these survivors, then, having the right hairstyle and being a part of the ‘cool’ crowd became small, insignificant concerns; staying healthy, spending time with their families, and reaching their educational and career goals were among the many new-found priorities reported during the interviews.

Despite these specific difficulties relating to peers, the majority of survivors described—in more general terms-- how they felt that their illness experience (and specifically the new perspective gained) had enhanced their sensitivity and compassion towards others. They came to “look at people in a whole different light, see how strong and good people can be,” to be “more understanding if a person doesn’t know what to say or do,” to feel “more in tune with what’s going on with other people,” and to want “to reach out and help cause you know, you’ve been there, you know how bad things can get.” Several survivors described how they often reached out to peers who were “different”, “unpopular”, or “geeky”, simply because they knew what it felt like to be an outsider. One survivor explained, “I think I was more able to understand other kids with problems. I was less likely to make fun of others and more likely to be friends with those that nobody else wanted to be friends with.”

This sensitivity and compassion toward others, even those on the fringe, lies in juxtaposition to the difficulties subsequently reported. It seems that while survivors generally feel more psychologically mature as a result of surviving cancer (reflected in reports of compassion and other-directedness), this maturity also creates specific difficulty relating to same-aged peers; the same maturity that compels them to want to help others may ultimately be distancing them from their peers.

### **3.2.1.2. Influence on romantic relationships**

As part and parcel of their newfound maturity and as further evidence of feeling different than their same-aged peers, many survivors discussed feeling like they knew what they wanted out of life—stable careers, marriage, family—long before their classmates and friends. Whereas attainment of these typical ‘adult goals’ is usually thought to become a priority in the late 20s (Jessor, Donovan, & Costa, 1991), the interviewees seemed to be on an accelerated path toward attaining their goals; they reported an urgency and a motivation to “go out and get em” and an unwillingness to “waste time.” At least half of the interviewed survivors, for example, expressed an unwillingness to engage in more casual romantic relationships that often characterize the high school and college years. One survivor recalled, “I didn’t really date in high school cause I didn’t think there was a point to it,” and another echoed her sentiment, “I think [cancer] is probably the reason I never really had boyfriends before cause I kinda go at life with the feeling that life is too short to really waste your time on things, so I never really wasted time on boys in high school because I thought it was stupid.” In describing her views on dating, another survivor cuts right to the chase: “Ultimately, I look to marriage. I don’t feel like I’m gonna date anybody unless I see myself spending the rest of my life with them. Otherwise it’s a waste of time.”

In the search for a compatible romantic partner, interviewed survivors-- almost without exception-- were looking for someone whose level of maturity, ambition, and direction rivaled their own. In describing her ideal partner, one survivor said, “The things I’ve been through have made me more mature, so someone who can handle more mature things than a normal 23 year old; when I date other 23 year olds, I end up with little boys.” A 19 year old survivor of Wilm’s tumor reported that she was already looking for “someone who has the same direction as me in life, someone who is looking toward marriage and is looking to have kids in the future.” She also revealed that these qualifications were hard to come by at such a young age: “I always seem to want more out of relationships than they do. And when you’re as young as I am, you can’t expect everyone to want to be in a committed relationship.” Several other survivors described past relationships with younger or same-age partners that were similarly unsuccessful as a result of mismatched priorities. One survivor ended a relationship with a boyfriend who was not “as responsible or mature as [she’d] like him to be, or as ambitious. He doesn’t want to be married until his 30s. Still living at home with his parents, doesn’t want to get out there and start paying rent on his own.” Another interviewee explained her most recent break-up, “I know what I’m doing. I have my plans set and he was just the total opposite and it drove me crazy.” In general, then, the disparity between the chronological age of survivors and their level of emotional maturity seems to present some challenges when it comes to developing and maintaining satisfying romantic relationships. At the same time, however, perhaps the focus on finding a more emotionally mature partner can be considered adaptive, as maturity may better equip an individual to process the survivors’ illness history, deal with and accept the reality of current physical sequelae, and cope with potential future implications (e.g., fertility, disease relapse).



In many cases, the newfound perspective gained from the illness experience appeared to benefit to the life of the relationship. The self-labeled “laid-back”, “life is too short” attitude may reduce the number of the minor arguments typically experienced by couples. One survivor explains, “A lot of the petty things that maybe people in relationships generally get into little arguments or bigger about, I realize are not really that big a deal and so not really much bothers me in relationships cause it has put things into perspective.” Another explains, “Usually a lot of things that some people argue about they’re really not worth arguing about.” These statements are consistent with quantitative findings that survivors tend to worry less than peers about non-cancer related issues (Langeveld et al., 2004; Weigers, Chelser, Zebrack, & Goldman, 1998). The question, however, is whether these individuals are truly experiencing less worry or whether they keep their true feelings to themselves in order to avoid conflict altogether (refer to subsequent section).

### **3.2.2. Self-Disclosure**

One level of intimacy identified in the literature involves personal self-disclosure—the expression of self-relevant feelings and information with another (Hook et al., 2003). Individuals differ in their ability to and willingness to self-disclose, and these differences have been linked to differences in relationship satisfaction. Willingness to self-disclose personal information—both cancer and noncancer related—was a frequent theme in the dialogues with participating survivors.

#### **3.2.2.1. Revealing cancer history**

In a review of the impact of cancer treatment on sexuality, intimacy, and relationships, Thaler-DeMers (2001) suggests that the issue of sharing one’s cancer history with a new partner is particularly salient to a young adult survivor population. Interview findings fully support this notion. Whether they reported being more or less willing to disclose their history, it was

apparent that the majority of interviewed survivors had given this issue a good deal of thought. With such a small sample, it is hard to identify characteristics of those who were eager to share their illness history from those who were more cautious.

About half of the survivors expressed a willingness—and even a desire-- to discuss their illness experiences with others, perhaps as a way to continue their own emotional processing of a difficult time in their past. One survivor reported, “It’s not hard for me to talk about now, not a problem. It’s something I’m happy about, for real, now.” Others stated, “I’ll tell anybody about it”, “I’m definitely very open about it. I usually just tell it like it is whenever the opportunity comes up,” and “It doesn’t really bother me to talk about what I went through at all.” Among these individuals who stated they were willing to discuss their illness, however, many displayed a moderate degree of ambivalence by qualifying their statements:

“It’s a part of my past that I don’t, it doesn’t bother me to talk about it or bring it up, but I don’t like to dwell on it too much.”

“I’m very open to that stuff, like talking about the basics—what I had, what I went through, like I lost my hair—like that I don’t mind. It’s just when it comes to questions like ‘well, how’d it make you feel back then?’, any of those questions, I’m like, I don’t know, less comfortable with.”

“It depends on if I’m talking about it from a clinical standpoint—it doesn’t really bother me, but if I’m talking about how it made me feel, it bothers me a little.”

These survivors seemed to indicate a level of comfort with disclosing their illness experience that had clear limits; whereas the clinical description of diagnosis and treatment seemed easy enough to discuss with friends and partners, going into greater depth and/or being asked to provide insight into their emotional response appeared far less welcome.

Many of the survivors who expressed a willingness to self-disclose their cancer history also reported being quite surprised and confused by, if not disappointed with, people's reactions. Interviewees were often struck by friends' and partners' apparent lack of curiosity or interest, their reluctance to ask questions or discuss it in any detail, and their tendency to change the subject and never bring it up again. One survivor was often displeased with how others "kinda blow it off like 'oh, that's too bad; my great grandfather died of cancer', like that's the same thing." Another explained,

"It's never something I hide from anyone I've ever gone out with. It's funny though, most every—no, EVERY person I've had a romantic relationship with-- none of them have ever wanted to talk about it; they don't want details, don't want to know anything about it. I don't know. It's like they don't care almost and don't want to know about it. Its hard because I don't think most people understand how much it truly impacts your life and how it completely changes you as a person—there's you before and you after. So you almost want to talk about it and tell people about it and answer people's questions, but as far as romantic relationships, nobody ever has. It's hard."

In trying to make sense of people's reactions, one survivor surmises, "It seems like those who are a little older, 30s, 40s, 50s, are the ones who want to know. It seems like younger people in this age group, it's like too much reality or something." An interesting question for future investigation is whether those survivors who were once willing to discuss their histories eventually come to refrain from doing so as a result of these previously disappointing reactions.

While half of the interviewed survivors reported an open willingness to discuss their cancer history with both romantic partners and friends, the other half described being more reluctant, if not outright fearful, of disclosing such a 'critical' piece of personal information.

These survivors acknowledged a fear of other's reactions as the main obstacle to being more open and honest. Consistent with the finding that 38% of single, young adult cancer survivors feel that their illness frightens people (Meadows et al., 1989), some interviewees worried that partners would not be able to handle such "heavy" and "loaded" information and therefore would be driven away:

"I don't know why but I'm always skeptical to tell people just cause of the scary stuff that comes with, well, even the word cancer."

"I feel like there are so few guys to pick from, that are attracted to me that I'm attracted to, that its like, this could easily be the deal-breaker that scares them away. My mom warned me about that, watch that information cause that's scary to some people."

"I was in a relationship for a year and a half and I had never even told him about it. I don't know, I guess before I had cancer, just hearing the word scared me—that's people's natural reaction."

Other survivors worried about how their friends and partners would perceive them after hearing about their illness. Specifically, they feared being viewed as different or weak and did not want others to feel sorry for or pity them:

"I don't know if it's that I don't want people to be sympathetic, or I just don't think people fully understand that that doesn't make you bad or different or unhealthy or whatever and I think a lot of people that's their initial reactions. I guess I'm afraid to tell people even in my regular friendships, I feel the same way....Maybe its cause its something that's still on my mind after so long, that I think that would be in the back of their minds and its not something I want someone to focus on about me."

“I don’t know, I just think people will really look at that as a weakness and that’s why that’s one thing I kinda like to hide.”

“I just didn’t want people to feel sorry for me. I just don’t think its that big of a deal. It’s just something my life threw at me and I had to deal with going through treatment and having surgery and I think if anybody was put in the situation, they would have done the same thing and I don’t want people to feel bad for me cause that happened and I don’t want them to look at me different.”

Interestingly, for those survivors who reported being more reluctant to reveal their cancer history, the virtual nonreaction of friends and partners was actually experienced as comforting. Others’ tendency to “not make a big deal out of it”, instead of being disappointing (as it had been among those more willing to self-disclose), appeared to be the preferred (and welcome) response. In discussing her increasing comfort with revealing her history, one survivor explained, “I think just seeing that more people just don’t care has helped.”

#### **3.2.2.2. Revealing emotions and personal thoughts**

Beyond self-disclosure of their cancer history, almost all of the interviewed survivors described a more general difficulty and/or cautiousness with sharing personal thoughts and feelings with friends and partners. Most interviewed women spoke of being viewed as ‘shy’ and ‘hard to get to know’ by both friends and romantic partners because they require a significant amount of time to open up, to be at ease communicating their innermost thoughts and feelings, and to feel comfortable asking for what they need in a relationship. Illustrative excerpts from the interviews include:

“I have a hard time getting close to people.... I feel like I’m holding back. My current boyfriend and my last boyfriend have both said that I’m hard to get to know.”

“It just takes me a little bit to open up to people. I never used to talk unless talked to. I just did what people told me to.”

“In terms of my personal feelings and thought, as long as they’re positive, I’m usually good about sharing them, but when things start to not go well, I kind of close up and don’t say anything.”

“Sometimes I don’t say as much as I need to. I’ll just let it go but then it builds up. Or I’ll just say the bare minimum and then let it go.”

Many survivors described how this tendency to bottle up emotions was often in an effort to avoid conflict with loved ones. One survivor, for example, admitted “I don’t like to deal with conflict, so usually if I have a problem, I’ll keep it to myself until it passes.” After discovering an incident of her partner’s dishonesty, one interviewee revealed, “I was pretty upset but I didn’t say I was upset. I just didn’t talk much about it at all, wasn’t sure if he would be bothered by me talking about it. When things aren’t going well, I don’t usually confront the situation.” Ironically, although not surprisingly, “keeping things to myself”, “not wanting to talk about my issues”, “holding things in until I blow up” was the most often cited source of conflict in survivor’s romantic relationships.

In thinking about their tendency to keep personal information to themselves or to bottle up negative emotions, many survivors spoke of how their illness experience may have played a role. In particular, not talking about their emotions at the time of diagnosis and treatment seemed to affect willingness and ability to talk years later, as one survivor recalled,

“For a while, I never really wanted to talk to anyone about it, even when I was going through my treatment. I was 11. I just really liked to kinda act like it wasn’t happening. There was really no one I confided in during that time, so even the years after it, someone

would bring something up to me about it, and I'd start crying and not even be able to talk about it, and not want to."

Another explained,

"I'm kinda an introvert when it comes to that type of stuff—thoughts, feelings, things that I want. I find it hard to talk about cause I always feel you should fend for yourself. Like my whole childhood, it was "well, we're not going to escalate this." Like when I had cancer, my mom took it hard, and I didn't want to over escalate anything. Like if it hurt a lot, I kinda just dealed. And I guess that's the same now, when I feel with something, I deal with it. Everybody has their downfalls and that's what I'd consider mine."

While a few survivors had difficulty explaining their tendency and desire to keep certain information private, the majority stated they felt they were acting in the best interest of those around them. Many discussed wanting to protect others from pain and worry and not wanting to burden them with their problems. Perhaps most poignantly, they described these tendencies as stemming from efforts to protect their parents during the days of their cancer treatment. One survivor explained,

"I'd have to say I was trying to protect the other people in my life. I just thought if I talked to other people about it, I'd kinda be burdening them with my problems. Like my parents and stuff, I felt bad that they even had to go through it with me, that I felt like if I was constantly talking to them about it, opening up, telling them my fears and everything, than they'd be more aware of that. And I don't know I thought I could keep going and handle it myself and I didn't want to have to burden other people. Sometimes it was just easier to keep it in."

Another recalled,

“I remember when I went through things, like a spinal tap, my mom wouldn’t come in the room, would sit in the hall and cry. For me it just was what it was. Something you deal with. But for her, it was something she had to see me deal with. And I didn’t want to make it harder for her- so I was like, ‘if I can help out in this way, I’ll just deal with it.’ I figured with all that was going on, if I could deal with this one thing, I could take that one thing off their minds.”

From the survivor interviews, it seems that this difficulty with self-disclosure generally appears to be more of a problem in romantic relationships than in same-sex friendships. One survivor revealed that she had difficulty expressing emotions with her boyfriend of 2 years but “not with the girls, it’s easier to talk to them. With guys, I’ve always had the problem of holding it in.” Another survivor who had trouble sharing personal information with her husband admitted, “I can tell my friends everything. I never have really held anything in, it’s never been a problem for me. My husband tells me I tell them too much about my life. I don’t know if it’s because they’re girls and I feel more comfortable.”

### **3.2.3. Body Image**

Another frequent theme that emerged from the interviews was physical self-consciousness as a result of treatment and treatment-related side effects. Over half of the interviewed survivors, particularly those diagnosed in adolescence and those with more severe physical sequelae, identified their negative body images as problematic in the formation of romantic relationships and the development of intimacy (both physical and emotional) within those relationships. In general, these survivors spoke of a desire not to feel different or stand out in any way and of how the physical changes of treatment made that difficult:

“I’m very self-conscious about my scars on my legs. I don’t wear skirts. I don’t wear shorts. I just always cover them up. It really bothers me.”



“[Side effects] are something I have to live with now and most of it is cosmetic and I worry that how I look people will notice that I’m different.”

“I have scars on my neck you can see all the time and ones on my chest I know are there. Has kinda kept me from wanting to get close to people.”

“I have a lot of health problems from my chemo, just side effects and stuff, and I get very self-conscious about it. There are things that I don’t tell people and things I didn’t tell [my partner] at first that I probably should have...like I had to get bridges cause my teeth never developed.”

Some survivors spoke specifically of how their negative body image affected their romantic relationships. One admitted,

“I’m very self-conscious about things just because of the physical, like, side effects, and I get very upset if my husband or anyone I have dated would say anything remotely close to something and they didn’t mean to be mean, but I’m very sensitive about certain things and that has caused fights or rifts in our relationship. And I know that it’s me cause I’m just very self-conscious about things.”

Another survivor explained,

“As far as my body image goes, I definitely have some self-confidence issues and that does affect your relationships. It hasn’t been anything that has caused my relationships to fail, but I think it definitely affects how close you can get to someone. And it may just take a longer time. There’s a lingering self-consciousness that comes with the territory. Physically, I think it may take me a little bit longer than other people to get into that intimate relationship. What do I think the fear is? Not embarrassment, not the right word at all. Its not that I don’t find myself attractive....but if you can’t look at your body and

be satisfied then it's kinda hard to allow someone else to look at it and expect them to be satisfied or them to look at in an, 'oh, she's perfect in my eyes' way, which is what every girl wants. If you're picking things out on your body that you don't like, like that scar or that place where my skin tone changed, you have a tendency to think that other people are all doing the same thing."

Like self-disclosure of private thoughts and emotions, body image did not seem as prominent a concern in survivors' same-sex friendships. Perhaps a greater degree of expected intimacy and/or the need to "impress" and feel physically attractive to one's partner makes physical self-consciousness more problematic in the context of romantic relationships. One interviewee explained, "There's something different there, and I don't know if it's because no matter what I look like, what happens to me, my friends are gonna be there. I don't really need my friends to think I'm attractive, I just need them to be my friends."

#### **3.2.4. Trust**

Many survivors were eager to speak of trust in their close relationships—both friendship and romantic. They appeared to represent both ends of the spectrum, as some described a tendency to trust others too quickly and others spoke of not being able to trust others enough. From the survivors' descriptions, it seemed that both of these tendencies were considered problematic in the development of satisfying and stable relationships. In addition, these attitudes seemed to be a result of interpersonal experiences with friends, families, and doctors at the time of treatment. More specifically, those survivors that had difficulty trusting others recalled:

"When I did get sick everybody left and I think that's still a fear of mine—that everybody's going to leave me."

"I don't think I value friendship as much and I know it has a lot to do with high school cause I remember thinking if these girls were really friends, they would have tried longer

to stay in touch, would have welcomed me back to school. They say they're your friend but are they really gonna be there through thick and thin?"

"Most of my doctors were male, they were the ones who did the surgery, started the chemo drips, took the blood. I would always cry when I went into the office cause I knew what was coming. So I think that is something, because there was that physical hurt—I was very close with them because I did trust them, I knew they knew what was best, but they had physically hurt me. I think that is still where some of my hesitance comes from, where I let myself go then pull back, let myself go then pull back. And I know clearly it wasn't to hurt me hurt me but I think that's why I have a harder time trusting males."

Other survivors who found it easier to trust others, explained:

"When you're sick and people are taking care of you, they're always putting your best interest first. That's how my family always was, friends, nurses. So I have this false sense of security. I just assume other people are going to be the same way, taking care of me. I think that's a little positive and negative. It's good cause I'm able to trust someone really easily, but it is a negative because I can sometimes think things are better than they are, go in a little too far, too fast."

"I'm a very trustworthy person and I just assumed he was being loyal even though I wasn't with him. That's one of my downfalls—I tend to trust people a little too quickly."

Whether the observed variability in survivors' capacity for interpersonal trust merely captures typical individual differences or truly represents a consequence of their experiences at the time of diagnosis and treatment, it seems significant that survivors themselves *perceive* their issues with trust as a consequence of childhood cancer.

### 3.2.5. Honesty and Communication

Honesty and communication, in both friendship and romantic relationships, appear to be highly valued by the interviewed survivors, as these were the qualities most often listed as components of an ideal relationship. While it seems likely that same-aged peers without chronic illnesses would also appreciate and look for honest communication in their interpersonal relationships, perhaps survivors *require* them for different reasons or place a higher level of importance on them. Dialogue from the interviews suggest this may be the case, as several survivors spoke of being kept in the dark during the time of their diagnosis and treatment and resenting that secrecy. Many recall being told they were sick but more clearly remember being shielded the majority of the specifics:

“I don’t remember being told in great detail exactly what was going on, like I only got the bare minimum.”

“People never told me the truth. They were always like, well, you’re sick, but they wouldn’t tell me how sick so I was always learning not to trust what people were saying.”

Perhaps as a result of this limited communication during a difficult and confusing time, survivors need their partners to be even more open and honest with them. One survivor listed “outright dishonesty” as unacceptable in her close relationships, and her definition of this outright dishonesty was quite revealing: “not telling me the truth on things or not telling me everything or just telling me parts of what I want to hear not the whole picture. I need to know the truth; I don’t need to know it after or when he thinks I can handle it.” In describing what she expects from a romantic partner, one survivor says, “I have to be able to trust that they would tell me things. Someone who is actually going to tell me how things are; I expect them to be honest with me.”, and another expects that her partner will not “just shut me out of the important stuff like when I was a kid.”

While most survivors expected complete honesty and openness of communication from their partners, many were unable to, or had great difficulty disclosing personal thoughts and emotions of their own. In other words, it appears that in some instances, survivors may expect something from their partners and friends that they themselves are unwilling to do. Whether this discrepancy in expected self-disclosure may be a source of conflict in relationships is an important question for further study.

### **3.2.6. Fertility and Family Issues**

Young adulthood is a time when individuals become concerned with settling down and starting families of their own. For survivors of childhood cancer, then, this can be a particularly difficult time, as concerns of infertility from chemotherapy and radiation and of having to deal with complications from treatment and the long-term effects of medications become more salient. It was not surprising, then, that all but one of the interviewed survivors reported significant worry about their ability to have children. While only one survivor was actively thinking of starting a family at the time of interview, even those who relatively young (19 yrs old) and those not currently in relationships identified fertility as a major concern. During the interviews, survivors discussed whether they would be able to have children and how their bodies would handle being pregnant:

“I would like to have kids someday, but with the type of cancer I had and the amount of radiation and chemo...I don’t know. There was a new study that just came out on Wilms' that said its very possible to get pregnant but then there are a lot of complications—like strain on the heart is a big problem.”

”I definitely think about it cause cancer is one thing, but I also have some problems that occurred kind of as complications and I am kind of afraid cause I feel like something about my body is not quite up to par.”

“I do worry sometimes about the health aspects, and its hard but then I think, well if its meant to be, then. Cause I don’t know, I have a lot of back problems because of my radiation that was right in my pelvic area. So I wonder how am I gonna be pregnant when my back hurts all the time now. I worry about that kind stuff.”

Survivors also expressed fears about the health of their future children, specifically that they could pass cancer on to their child or that their radiation and chemotherapy treatments may result in a child born with some sort of physical, mental, and/or learning disability:

“The fear I have is that the cancer that I had is genetic. So there’s a good chance that they would have it.”

“And I do get nervous that if I do have kids there might be something wrong with them and it would be because of me.”

“And I worry, oh no, cancer is hereditary sometimes, like what if my children, I would feel like I was the one who gave it to them.”

Several survivors in serious long-term relationships admitted that this was a difficult topic to discuss with their partners:

“I always wonder, worry that maybe I would have a child that would have something wrong with it. And I worry I might not be able to have children. Its always a constant thought. Its just the fact that I know that if it can happen to me than it can happen to anyone. You never have that feeling of being superhuman that most people my age do. I’ve mentioned it to my fiancé but he really doesn’t seem concerned too much. He probably just doesn’t understand.”

“Yes, we do want to have kids, not for a couple years, but... I do worry sometimes... and I probably should talk to my husband about it but I don’t think I ever have...It’s almost

like I don't talk about it so it won't become an issue; if I don't talk about it, it won't happen."

These findings are consistent with several quantitative studies reporting that survivors, relative to healthy peers, worry more about their reproductive capacity and health of their future children (Gray et al, 1992; Langeveld et al., 2004; Wasserman et al., 1987; Weigers et al, 1998). In addition, the two subthemes of reproductive capacity and concerns about children's health have been identified in an earlier qualitative study of young adult survivors (Zebrack et al., 2002).

## **4. Discussion**

### **4.1. Summary of Findings**

Quantitative results revealed that when compared with controls, young adult survivors of childhood cancer were involved in fewer romantic relationships over the past five years and were significantly more distressed at the dissolution of those relationships. No other group differences were found for the friendship and romantic relationship outcome variables. Compared with controls, survivors diagnosed in adolescence had significantly fewer relationships in the last five years. Survivors who received ‘severe’ treatment intensity ratings, relative to both controls and survivors with ‘mild’ and ‘moderate’ treatment intensities, reported fewer relationships overall and more distress at break-up, as well as lower satisfaction in both romantic and friendship relationships. Within the survivor sample, results suggest that high trait anxiety, male gender, an older age of diagnosis, and higher treatment intensity are risk factors for relationship difficulties, including lower relationship satisfaction, lower levels of reported intimacy, greater fear of intimacy, more conflict, and more distress at break-up.

Qualitative interviews, conducted with 18 female survivors of childhood cancer, revealed a number of relationship issues not captured by the quantitative measures employed in this study or other investigations of young adult survivors. These issues included perceptions of others as lacking emotional maturity and related feelings of isolation from peers, reluctance to engage in casual dating, cautiousness with self-disclosure of negative emotions and personal experiences, self-consciousness as a result of treatment-related physical changes, and concerns about fertility.

A notable discrepancy was observed between the quantitative data and impressions derived from the qualitative interviews. In isolation, quantitative results (specifically, the *lack* of main effects) suggest a certain degree of resilience, or recovery of function, among young adult survivors of childhood cancer and therefore are consistent with studies reporting no differences in



psychosocial sequelae between survivors and population norms or non-diseased control groups (e.g., Kazak et al., 1994; Kupst et al., 1995). These results confirm that for childhood cancer survivors, like other groups of children growing up in the midst of chronic adversity, resilience-- rather than being an extraordinary phenomenon-- is a quite common process (Garmezy, 1974; Masten, 2001). Exposure to environments characterized by high psychosocial stress, then, does not necessitate psychopathology (Masten & Coatsworth, 1998).

This 'psychosocial hardiness' interpretation, however, is challenged by the current qualitative results which clearly indicate a number of difficulties in close relationships among young adult survivors. For example, while no group differences emerged on the quantitative measures of intimacy and fear of intimacy, interviews with survivors revealed substantial perceived difficulty with self-disclosure, an important (and essential) component of intimacy (Clark & Reis, 1988; Hook et al., 2003). Furthermore, *all* of the interviewed survivors, even those maintaining a generally positive worldview and reporting a high degree of relationship satisfaction on the quantitative measures, identified at least one area of difficulty in their close relationships. Over two thirds (13/18) described two or more difficulties, and 11/18 described three or more.

Reasons for the discrepant quantitative and qualitative findings are unclear. One possible explanation is that the level of relationship difficulty expressed by the cancer survivors is normative for this age group, and a similar level of difficulty in close relationships would be endorsed by healthy controls had they been interviewed. However, the qualitative responses of the cancer survivors suggest that this is not the sole explanation, as they clearly linked their current relationship difficulties to their past history of cancer. Although it remains possible that this reflects a cognitive bias rather than experiential differences, it is also possible that the quantitative measures employed in this study failed to address relationship issues and concerns

of salience to childhood cancer survivors. In this regard, the qualitative findings can be used as a guide to inform the development of relationship measures and to generate theoretically-driven, testable hypotheses. Based on the qualitative findings from the current study, a number of important areas for future research can be identified. These include examination of whether 1) survivors' perception of their emotional maturity contributes to feelings of loneliness and social isolation from peers, 2) survivors dating practices and seemingly precocious focus on marriage differs from their peers, 3) the perception of a negative body image predicts lower relationship satisfaction in young adult survivors, particularly those diagnosed in adolescence, 4) communication practices at the time of diagnosis and treatment (from parents and doctors) impact survivors' willingness to and comfort with disclosing their history to current friends and partners, and 5) survivors' discomfort with self-disclosure contributes to relationship satisfaction and conflict.

In addition to providing directions for future research, the qualitative findings offer some possible insight into the fewer number of relationships and greater distress at break-up endorsed by survivors when compared with controls. Responses in the qualitative interviews suggest that fewer relationships may be a consequence of perceptions of being 'hard to get to know', of difficulty finding mature, like-minded partners, and of not wanting to 'waste time' in romantic relationships with 'no future'. Interview findings also suggest that survivors may be less likely to experiment with more casual romantic relationships than their peers, as they are more focused on finding someone with whom they can spend the rest of their lives. If survivors are looking to marriage, it makes intuitive sense that the end of a relationship would be experienced as more painful. More distress may also account for the group difference in number of relationships, as

survivors may require more time to mourn the loss of their partner, process the relationship as a whole, and resume dating.

A number of previous studies have reported lower rates of marriage among survivors relative to controls (Langeveld et al., 2003; Rauck et al, 1999), but participants, on the whole, were significantly older than those in the present study (ages range from 16-49). While differential rates of marriage were not present in this sample, the findings of fewer relationships in the last five years and more felt distress at relationship end, in fact, may be early indicators of and/or contributors to lower marriage rates that may emerge as this relatively young sample ages. As such, continuing to follow survivors through young adulthood will be an important direction for future research in determining the ultimate significance of these main effects.

#### **4.1.1. Moderators of Relationship Outcomes**

A number of individual factors and illness/treatment-related variables, specifically high trait anxiety, male gender, an older age of diagnosis, and higher treatment intensity, emerged as significant predictors of relationship difficulties in young adult survivors of childhood cancer. These results indicate that certain subsets of survivors are at greater risk of difficulties in their close relationships than others. Consistent with a developmental psychopathology framework, then, the relationship between childhood cancer and later relationship difficulties is not simply linear; social adjustment to childhood cancer cannot be predicted from a single source of influence at a single point in time (Cicchetti & Cohen, 1995). The picture is far more complex, with a number of risk factors (and the interactions among them) contributing to long-term sequelae. Furthermore, the pattern of results found within the survivor group supports the notion of ‘cumulative risk’, with risk factors having additive effects when they co-occur (Masten, Best, & Garmezy, 1990; Sameroff & Seifer, 1990) such that the combination of two or more risk factors has greater deleterious impact than the sum of the factors considered in isolation from each other

(Pellegrini, 1990). Thus, it is not simply the experience of childhood cancer that predisposes an individual to relationship difficulties, but the interaction of that experience with multiple individual difference and illness variables like trait anxiety, gender, treatment intensity, and age of diagnosis.

#### **4.1.1.1. Trait anxiety**

While there were no group differences in trait anxiety in this study, higher trait anxiety among survivors was related to lower relationship satisfaction, greater fear of intimacy, and higher levels of conflict. Individual differences in ‘anxiety proneness’ (Spielberger, 1972) may contribute to problems in close relationships via a number of associated cognitive biases. For example, individuals with high levels of general anxiety have been shown to demonstrate an attentional bias toward irrelevant but threatening stimuli and a bias toward interpreting ambiguous situations as threatening. These biases result in increased threat perception and lower threat thresholds (Muris, Merckelbach, & van Spauwen, 2003; Muris, Rapee, Meesters, Schouten, & Greers, 2003). In addition, research reveals that relative to healthy controls, clinically anxious adults estimate future negative events as far more likely to occur (Butler & Mathews, 1983).

In light of this research, it seems likely that childhood cancer survivors with high trait anxiety may perceive a variety of social situations and social cues as threatening or intimidating. For example, they may construe a seemingly innocuous event (minor argument, not having received a phone call, comment about physical appearance) as more threatening to the stability of the relationship. While these biases are not specific to cancer survivors and could be demonstrated by anyone with high trait anxiety, results (i.e., illness group by trait anxiety interaction) suggest that they may be exacerbated by the stressors and challenges of the cancer

experience. For example, if a survivor high in trait anxiety maintains a negative body image perception as a result of treatment-related changes and medical sequelae, he or she may be particularly sensitive to peers' comments about or preoccupation with appearance or intimidated by a partner's physical advances. Similarly, the perception of not fitting in with peers may be complicated by trait anxiety via a hypervigilance to peers' social cues and a tendency to prescribe additional meaning to otherwise innocuous events. If the cancer experience results in difficulty trusting others, high trait anxiety may make a survivor even more suspicious of a partner's words and actions. This interpretation is supported by the current qualitative findings, as several interviewed survivors discussed instances of hypersensitivity to their partners' and friends' social cues and verbal comments (particularly in relation to body image and the ability to trust others). Future research should examine these cognitive biases as potential mediators of the relationship between childhood cancer and relationship difficulties.

#### **4.1.1.2. Age of diagnosis**

Results from the present study indicate that diagnosis during adolescence is related to fewer relationships overall, lower relationship satisfaction, and greater fear of intimacy than diagnosis at younger ages. These findings are consistent with research that has found an older age of diagnosis to be related to poorer overall coping (Kupst et al., 1995) and long-term adjustment (Koocher & O'Malley, 1981), including lower social quality of life among young adult survivors (16-28 years old) (Zebrack & Chesler, 2002). While the processes that may explain this age effect remain unclear, there are a number of likely possibilities. Findings of more reported relationship difficulties among those diagnosed in adolescence may be a result of less time having passed since treatment end. Having been diagnosed more recently, these survivors have not had as much time to adjust to the period of survivorship. They still may be

processing their experience and coming to terms with its meaning in their life and future relationships. Those who are longer-term survivors have had more years to reflect on their illness relative to other life experiences and assign it relative meaning (Hobbie et al., 2000). In addition, appraisal of the cancer experience is highly dependent on developmental level (Peterson, 1989), so individuals diagnosed in adolescence possess greater cognitive maturity and, therefore, are likely to process their experience in a different way than those diagnosed at earlier ages.

Diagnosis and treatment during adolescence may present a greater risk for the development of future relationship difficulties because it is a developmental period marked by significant social development (i.e., increased focus on peer relations and increasing sexual interest). Missing significant periods of school and reverting to greater dependency on caregivers, adolescents with cancer can lose valuable opportunities for social interaction, the development of autonomy, and integration into the world of their peers. In addition, as adolescents place more attention on appearance than younger age groups and engage in increased social comparison, physical self-consciousness may be exacerbated in adolescents with cancer (Kazak & Stuber, 1999). Indeed, body image concerns have been associated with poorer social adjustment, avoidance of social situations, negative peer relations, decreased activities with peers, and poor self esteem (e.g., Brooks-Gunn & Peterson 1983; Rauste-von Wright, 1989).

Support for the negative impact of school absences, decreased peer interactions, and increased body self-consciousness on relationships among individuals diagnosed with cancer during adolescence comes from the qualitative interviews. Here, survivors' recollections of returning to school after treatment focused on difficulty fitting in with and relating to peers as a consequence of missing so much school. In addition, treatment related physical changes (i.e., hair loss, weight gain) and medical sequelae were frequently identified as contributing to

negative body image perceptions, and, in turn, to relationships difficulties like fear of physical intimacy. Qualitative work focusing specifically on individuals diagnosed in adolescence will be necessary to further investigate these (and other) developmentally-specific pathways to relationship difficulties.

#### **4.1.1.3. Treatment intensity**

Results indicate that survivors who experienced the most severe treatment protocols were involved in the fewest number of romantic relationships and reported the lowest levels of both friendship and romantic relationship satisfaction, the greatest levels of distress at break-up, and (in combination with trait anxiety) the lowest levels of intimacy. These findings are consistent with several studies that have found a significant association between severity of treatment and later maladjustment, including socialization difficulties (Butler et al., 1999; Reiter-Purtill et al., 2003). More intense treatment often requires multiple, lengthy hospitalizations, more missed school, and greater restriction of social activities. Opportunities for peer interactions (and therefore the development of close interpersonal relationships) are significantly reduced. Furthermore, patients who experience more intense treatment are at increased risk for future physical health problems (Zebrack & Chesler, 2002), and these physical problems likely contribute to ongoing social disruption. Finally, greater treatment severity increases risk of neurocognitive impairment (Zebrack et al., 2002). Dosage of cranial irradiation, for example, has been related to nonverbal intelligence deficits (Butler et al., 1999; Zebrack et al., 2002) that in turn may result in greater socialization difficulties (Butler et al., 1999). Future assessment of survivors who experienced varying levels of treatment intensity will help clarify the processes underlying risk for future relationship difficulties.

#### **4.1.1.4. Gender**

In the present study, male survivors reported the fewest number of relationships overall and, in combination with trait anxiety, lower romantic relationship satisfaction and higher levels of conflict. These findings are inconsistent with studies that identify females as reporting more symptoms (Stuber et al., 1997; Zeltzer et al., 1997) and having more parent-rated socialization difficulties (Butler et al., 1999). As there was a trend ( $p = .06$ ) for the male survivors in the sample to report higher levels of trait anxiety, trait anxiety, rather than gender, may be primarily accounting for the variance in outcome. This conclusion is supported by multivariate analyses that show no independent effect of sex on relationship outcomes when level of trait anxiety is entered in a prior step of the model. Robust conclusions about observed gender differences, then, cannot be drawn at this time. To confirm the presence of gender-specific relationship difficulties among survivors and assess their ultimate significance, qualitative interviews with male survivors are indicated.

## **4.2. Study Limitations**

### **4.2.1. Measurement Considerations**

As noted above, a number of limitations in the quantitative assessment of relationships may have contributed to the observed inconsistencies with qualitative findings. The majority of the romantic relationship measures (satisfaction, expectations, and intimacy) involved the participant identifying and addressing their single most significant past or present relationship. Unfortunately, this methodology may have caused bias in responding. Respondents may consider their most significant relationship to be their “best” relationship, especially if it is the one in which they are currently involved. Participants may exhibit a recency bias and inflate their evaluation of a current relationship, as it has not been tainted by the distress experienced at relationship end. Moreover, they may be more likely to report positive feelings at the beginning



of a relationship, during the aptly named ‘honeymoon’ period. In the present study, 58% of the sample reported on a current relationship. Overall, assessments of current relationships were more positive than those of past relationships, but this pattern did not differ between groups. Given the potential bias introduced through the evaluation of a single relationship, group differences on other relationship variables less susceptible to this bias (e.g., a count of # relationships in the last five years, levels of distress at break-up, and conflict averaged over the total number of relationships) may provide more reliable indicators of relationship difficulties. Interestingly, these are the measures that tended to show a difference between survivors and controls. Thus, further investigation of more general measures of relationship quality is indicated.

In this study, high correlations between the different relationship measures (see Tables 5 and 8) suggest that instead of measuring distinct components of relationship quality (as outlined in the proposed model, Figure 1), the Relationship Assessment Scale, Expectations for Partner, and Miller Social Intimacy Scale, all seem to be tapping a single underlying construct. This conclusion was supported by a principal components factor analysis, which showed that the three measures loaded highly on a single factor. Whether this is a function of shared method variance (with responses to each measure being based on self-report of the same relationship), or a function of poorly operationalized constructs of satisfaction, expectations, and intimacy, teasing apart components of relationship quality is not possible in this sample. Perhaps the validity of these constructs needs to be reevaluated. Relationship satisfaction, for example, may not simply be affected by whether expectations are high or low but whether the individual feels that his or her original expectations are being met. Similarly, the level of intimacy in a relationship may not be as important as the amount of discrepancy between desired intimacy and felt intimacy.

Finally, as empirical studies suggest, average level of conflict may not be as valuable an indicator of overall relationship quality as how that conflict is managed (Gottman, 1994).

#### **4.2.2. Sampling considerations**

The survivor sample in this study was recruited via two mass mailings to former CHP patients meeting eligibility criteria. The content of the recruitment materials may have led to a response bias, as the initial contact letter invited survivors to participate in a ‘study of young adult close relationships’. It is impossible to discern whether survivors with impaired social relationships were more or less likely to participate than those survivors with fewer difficulties. Responders may have also differed from nonresponders on key illness and treatment-related variables like treatment intensity and degree of medical sequelae/functional impairment. Given that participation rate was slightly less than 10%, results of this study may not be generalizable to the larger group of young adult survivors of childhood cancer.

While a sample of 60 young adult survivors is large in comparison with the existing literature, there was limited power to detect significant interactions. Power was sufficient (at least .80) to detect moderately-sized interaction effects (Aiken & West, 1991) at  $\alpha = .05$ , but the study was underpowered to detect small effects. In addition, given the pattern of risk factors found in this study, it seems likely that three-way interactions exist in the data, but a much larger sample size would be required to detect such higher order associations (e.g., for a three-way interaction of large effect size, approximately 200 cases are required, and for those of moderate effect size, approximately 500 cases are required; Dawson & Richter, 2004). Given the relatively low incidence of pediatric cancer, investigators must move toward multi-site collaboration in order to recruit adequate sample sizes for the detection of such effects.

Like most studies on the psychosocial effects of treatment for childhood cancer, this study included individuals who survived a range of pediatric malignancies. In combination with the

relatively small sample size, the ability to investigate adjustment in relation to specific diseases is quite limited. Some studies have suggested that longer term outcome may be specific to type of cancer and related treatment intensity (Hudson et al., 2003; Sanger et al., 1991; Sloper et al., 1991), but future studies are necessary before conclusions can be drawn about disease-specific risk. In addition, as this study utilized treatment intensity ratings that were clinical judgments on a composite of multiple treatment variables (surgery, chemotherapy, radiation, BMT, etc.), it is limited in its ability to determine which specific modalities may be most important in determining long-term risk for relationship difficulties. Finally, in regard to disease and treatment variables, this study did not include a measure of physical impairment (i.e., limb amputation, sensory difficulties) or functional impairment (i.e., interference with normal activities for age). As previous studies have found these variables to be related to a number of negative sequelae, including relationship difficulties like insecurity and ambivalence (Joubert et al., 2001) and other problems likely to affect close relationships like negative body image (Anholt et al., 1993; Pendley et al., 1997), degree of functional/physical impairment is an important variable to include in future research.

While the qualitative findings are compelling, they too are limited by a number of factors. Only female participants were invited to participate in this portion of the study and therefore findings are not generalizable to male survivors. With 18 out of 40 female survivors agreeing to be interviewed, this sample is likely influenced by self-selection bias, and there may be important differences between responders and nonresponders. While analyses indicate that there were no differences between female survivors who agreed to participate and those who did not on demographic, treatment, and relationship variables, there was a trend ( $p = .06$ ) for interviewed females to have higher trait anxiety. As quantitative analyses suggest trait anxiety as a risk factor for future relationship difficulties, the interviews may have been biased toward greater

endorsement of problems. In addition, there may have been differences between responders and nonresponders on other variables not measured. Finally, the qualitative findings are limited by the lack of a control group, thus it is unclear whether the relationship difficulties endorsed by this group are specific to survivors of childhood cancer or not. For this reason, future research would benefit from the inclusion of a normative control group of the same age.

### **4.3. Future Directions**

The current study clearly emphasizes the need for qualitative research that further explores the nature of close relationships among young adult survivors of childhood cancer. By continuing to reveal issues most pertinent to survivors' social QoL, this research will aid in the development of more sophisticated relationship assessment measures. In addition, as discussed earlier, current qualitative findings support quantitative exploration of a number of relationship themes and related issues, including perceptions of emotional maturity, negative body image beliefs, trust and communication, self-disclosure of personal feelings and experiences, and fears about fertility.

The quantitative findings presented here suggest that trait anxiety, treatment intensity, and age of diagnosis are predictors of relationship difficulties among survivors of childhood cancer. Future directions for research include the examination of additional risk and protective factors that may initiate and maintain trajectories toward both negative and positive relationship outcomes. Possible factors for consideration include SES, IQ, perceived social support (both at the time of diagnosis and assessment), and degree of physical sequelae/functional impairment. In addition, as many interviewed survivors spoke of their relationships with their parents at the time of diagnosis as influential in the development and maintenance of current romantic and

friendship relationships, investigations of various aspects of the parent-child relationship at the time of treatment (i.e., parenting practices, communication, etc.) are warranted.

Ongoing evidence in the field of adjustment following childhood cancer points to a need for more sophisticated and appropriate measures (Eiser et al., 2000; Kazak, 1994; Stam et al. 2001). Our findings provide further support for a need to reevaluate assessment tools and to focus on issues raised by qualitative data. Studies frequently rely on measures not validated for medical populations and/or those designed to assess clinical levels of psychopathology. While there are obvious benefits to using such standardized and well-known instruments, they ultimately may miss specific illness-related sequelae (e.g., fertility fears) and more subtle adjustment difficulties experienced by survivors—difficulties that while not pathological, may still greatly affect various aspects of quality of life. To date, there are few well-validated or widely used population-specific instruments to measure quality of life in childhood cancer *survivors* (Feeny et al., 1992; Ferrans & Powers, 1992), and none (to this author’s knowledge) focused specifically on an in-depth assessment of social relationships. Findings from the current study clearly indicate that qualitative methods (e.g., additional interviews, focus groups) are crucial to the construction of new measures that more accurately evaluate social QoL among childhood cancer survivors.

While using a healthy control group highlights differences between those with and without an illness history, using another chronic illness group as the comparison group evaluates a different, yet equally important question—whether there is something specific about childhood cancer that predisposes survivors to long-term relationship sequelae. Future research with other illness populations (e.g., cystic fibrosis, epilepsy, diabetes), then, could evaluate whether the type of chronic illness a child experiences has differential effects on his or her future relationships.

In order to address the limitation of shared method variance and to gain a more complete understanding of close relationships among survivors, future studies that rely on more than self-report of survivors are necessary. Incorporating collateral reporters (i.e., close friends and/or romantic partners) would allow for important comparisons between self- and other- report on various relationship issues. Observations of interpersonal interactions between survivors and their friends and survivors and their romantic partners would provide real-time, objective measures of communication, conflict management, and other interpersonal skills.

Finally, this study was cross-sectional and therefore limited in its ability to trace individual outcome trajectories and to chart the emergence and progression of close relationships as more time passes from the completion of treatment. Longitudinal work is essential to address the processes underlying developmental change in close relationships of survivors, as patterns of continuity and change cannot be revealed with cross-sectional data.

#### **4.4. Clinical Implications and Conclusion**

A first step to successful intervention is identifying those children who are at substantial risk for future difficulties. Results from this study support targeting patients with high levels of trait anxiety, who are diagnosed at older ages and/or subjected to more severe treatment protocols. Survivors' poignant memories of not having anyone to talk to, of bottling up their fear and sadness to protect their parents, and of returning to school and having difficulty fitting in, indicate a need for greater support during the time of treatment. Developmentally appropriate support groups would create a safe environment and outlet for patients to express their fears and negative emotions, provide valuable social opportunities and peer interaction, and encourage relationships between patients. In addition, these groups could provide patients with strategies for talking to friends about their illness, for staying in touch with them over the course of

treatment, and for coping with potential feelings of isolation upon return to school. As patients transition into the phase of survivorship, they would likely benefit from participation in ongoing support groups where they can meet other survivors, share mutual concerns, and form more intimate relationships. Finally, long term survivors' clinics could provide periodic workshops aimed at working on the communication of specific cancer-related issues to friends and romantic partners (e.g., how do you share your illness history?; what kinds of reactions can you expect and how will you handle them?; when is a good time to discuss fertility concerns with your partner?; how would that conversation go?).

The cancer experience does not end when treatment is discontinued. New physical, emotional, and social challenges accompany the transition to survivorship and continue to emerge and evolve over time. In this way, then, survivorship is not a static concept, but rather a dynamic, life-long process involving an accumulation of responses to changes that have evolved from diagnosis and treatment (Pelusi, 1997). Developmentally-sensitive research utilizing multiple methods of assessment will continue to provide insight into this process of survivorship, into the constantly evolving issues and concerns of childhood cancer survivors. The knowledge gained will better prepare patients and families for the long-term impact of surviving a life-threatening illness and will assist in the development and implementation of effective, targeted strategies for maximizing survivors' QoL (social and otherwise) as they continue to mature and as more time passes from initial diagnosis.

## 5. References

- Aida, Y., & Falbo, T. (1991). Relationships between marital satisfaction, resources, and power strategies. *Sex Roles, 24*, 43-56.
- Aiken, L.S., & West, S.G. (1991). *Multiple regression: Testing and interpreting interactions*. Newbury Park: Sage.
- American Cancer Society (2005). *Cancer Facts and Figures 2005*. Atlanta, GA: American Cancer Society.
- Anholt, U. V., Fritz, G. K., & Keener, M. (1993). Self-concept in survivors of childhood and adolescent cancer. *Journal of Psychosocial Oncology, 11(1)*, 1-16.
- Apter, A., Faberstein, I., & Yaniv, I. (2003). Psychiatric aspects of pediatric cancer. *Child and Adolescent Psychiatric Clinics of North America, 12(3)*, 473-492.
- Asher, S.R., Renshaw, P.D., & Geraci, R.L. (1980). Children's friendships and social competence. *International Journal of Psycholinguistics, 7(1-2)*, 27-39.
- Auerbach, C.F. & Silverstein, L.B. (2003). *Qualitative data: An introduction to coding and analysis*. New York: New York University Press.
- Bagwell, C.L, Newcomb, A.F., Bukowski, W.M. (1996) Preadolescent friendship and peer rejection as predictors of adult adjustment. *Child Development, 69(1)* 140-153.
- Barakat, L. P., Kazak, A. E., Meadows, A. T., Casey, R., Meeske, K., & Stuber, M. L. (1997). Families surviving childhood cancer: A comparison of posttraumatic stress symptoms with families of healthy children. *Journal of Pediatric Psychology, 22(6)*, 843-859.
- Baron, R.M., & Kenny, D.A. (1986). The moderator-mediator distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*, 1173-1182.



- Barth, R.J., & Kinder, B.N. (1988). A theoretical analysis of sex differences in same-sex friendships. *Sex Roles, 19*, 349-363.
- Baucom, D.H., Epstein, N., Rankin, L.A., & Burnett, C.K. (1996). Assessing relationship standards: The Inventory of Specific Relationship Standards. *Journal of Family Psychology, 10*, 72-88.
- Baumeister, R.F., & Leary, M.R. (1995). The need to belong: Desire for interpersonal attachment as a fundamental human motivation. *Psychological Bulletin, 117*, 497-529.
- Berkman, L.F., & Syme, S.L. (1979). Social networks, host resistance, and mortality: A one-year follow-up study of Alameda County residents. *American Journal of Epidemiology, 109*, 186-204.
- Bhatia, S., Blatt, J., & Meadows, A. (2004). Late effects of childhood cancer and its treatment. In P.A. Pizzo & D.G. Poplack (Eds.), *Principles and Practice of Pediatric Oncology, 4<sup>th</sup> ed.* (pp. 1431-1462). Philadelphia: Lippincott, Williams, & Wilkins.
- Bippus, A.M., & Rollin, E. (2003). Attachment style differences in relational maintenance and conflict behaviors: Friends' perceptions. *Communication Reports, 16*(2), 113-123.
- Bowlby, J. (1969). *Attachment and Loss (Vol. 1)*. New York: Basic Books.
- Brehm, S.S. (1992). *Intimate relationships*. New York: McGraw-Hill.
- Brooks-Gunn, J., & Peterson, A.C. (Eds.). (1983). *Girls at puberty: Biological and psychosocial perspectives*. New York: Plenum Press.
- Buhrmester, D., & Furman, W. (1986). The changing functions of friends in childhood: A neo-Sullivanian perspective. In V.J. Derlega & B.A. Winstead (Eds.), *Friendships and social interaction* (pp. 41-62). New York: Springer.

- Butler, G., & Mathews, A. (1983). Cognitive processes in anxiety. *Advances in Behavior Research and Therapy*, 5, 51-62.
- Bulter, R.W., Rizzi, L.P., & Bandilla, E.B. (1999). The effects of childhood cancer and its treatment on two objective measures of psychological functioning. *Children's Health Care*, 28(4), 311-327.
- Canary, D.J., & Cupach, W.R. (1988). Relational and episodic characteristics associated with conflict tactics. *Journal of Social and Personal Relationships*, 5, 305-325.
- Cicchetti, D. & Cohen, D.J. (1995). Perspectives on developmental psychopathology. In D. Cicchetti & D.J. Cohen (Eds.), *Developmental psychopathology: Vol. 1. Theory and methods* (pp. 3-20). New York: Wiley.
- Charlton, A., Larcombe, I.J., Meller, S.T., Morris Jones, P.H., Mott, M.G., Pottan, M.W., Tranmer, M.D., and Walker, J.J.P. (1991). Absence from school related to cancer and other chronic conditions. *Archives of Disease in Childhood*, 66, 1217-1222.
- Clark, M.S., & Reis, H.T. (1988). Interpersonal processes in close relationships. *Annual Reviews in Psychology*, 39, 609-72.
- Cohen, J. (1988). *Statistical power analysis in the behavioral sciences* (2<sup>nd</sup> ed.). Hillsdale, NJ: Erlbaum.
- Cohen, S. (2004). Social relationships and health. *American Psychologist*, 59(8), 676-684.
- Cohen, S. (1988). Psychosocial models of social support in the etiology of physical disease. *Health Psychology*, 7, 269-297.

- Dawson, J.F., & Richter, A.W. (2004). A significance test of slope differences for three-way interactions in moderated multiple regression analysis. Retrieved June 25, 2006 from Aston Business School Web site: <http://www.abs.aston.ac.uk/newweb/research/publications/docs/RP0422.pdf>
- Delongis, A., Folkman, S., & Lazarus, R.S. (1988). The impact of daily stress on health and mood: Psychological and social resources as mediators. *Journal of Personality and Social Psychology*, 54, 486-495.
- Descutner, C.J. & Thelen, M.H. (1991). Development and validation of a fear-of intimacy scale. *Psychological Assessment*, 3(2), 218-225.
- Dolgin, M.J., Somer, E., Buchvald, E., & Ziazov, R. (1999). Quality of life in adult survivors of childhood cancer. *Social Work in Health Care*, 28(4), 31-43.
- Eidelson, R.J., & Epstein, N. (1982). Cognition and relationship maladjustment: Development of a measure of dysfunctional relationship beliefs. *Journal of Consulting and Clinical Psychology*, 50, 715-720.
- Eiser, C. (1993). *Growing up with a chronic disease: The impact on children and their families*. London: Jessica Kingsley Publishers.
- Eiser, C., & Havermans, T. (1994). Long term social adjustment after treatment for childhood cancer. *Archives of Disease in Childhood*, 70, 66-70.
- Eiser, C., Hill, J.J., & Vance, Y.H. (2000). Examining the psychological consequences of surviving childhood cancer: Systematic review as a research method in pediatric psychology. *Journal of Pediatric Psychology*, 25(6), 449-460.

- Elkin, T. D., Phipps, S., Mulhern, R. K., & Fairclough, D. (1997). Psychological functioning of adolescent and young adult survivors of pediatric malignancy. *Medical and Pediatric Oncology*, 29, 582-588.
- Emmons, R.A. & Colby, P.M. (1995). Emotional conflict and well-being: Relation to perceived availability, daily utilization, and observer reports of social support. *Journal of Personality and Social Psychology*, 68(5), 947-959.
- Erikson, E.H. (1964). *Childhood and society*. New York: Norton.
- Erikson, E.H. (1959). Identity and the life cycle: Selected papers. *Psychological Issues*, 1, 1-171.
- Erickson, S. J., & Steiner, H. (1999). Somatization as an indicator of trauma adaptation in long-term pediatric cancer survivors. *Clinical Child Psychology and Psychiatry*, 4(3), 415-426.
- Feeny, D., Furlong, W., Barr, R.D., Torrance, G.W., Rosenbaum, P., & Weitzman, S. (1992). A comprehensive multiattribute system for classifying the health status of survivors of childhood cancer. *Journal of Clinical Oncology*, 10, 923-928.
- Ferrans, C.E., & Powers, M.J. (1992). Psychometric assessment of the quality of life index. *Research in Nursing Health*, 15, 29-38.
- Fletcher, G.J.O., Simpson, J.A., & Thomas, G. (2000). Ideals, perceptions, and evaluations in early relationship development. *Journal of Personality and Social Psychology*, 79, 933-940.
- Fox, J. (1991). *Regression diagnostics*. Newbury Park: Sage.
- Fox, M., Gibbs, M., & Auerbach, D. (1985). Age and gender dimensions of friendship. *Psychology of Women Quarterly*, 9, 489-501.

- Garnezy, N. (1974). The study of competence in children at risk for severe psychopathology. In E.J. Anthony & C. Koupernik (Eds.), *The child in his family* (pp. 77-98). New York: Wiley.
- Gottman, J.M. (1994). *What predicts divorce? The relationship between marital processes and marital outcomes*. Hillsdale, NJ: Lawrence Erlbaum.
- Grabill, C.M., & Kerns, K.A. (2000). Attachment style and intimacy in friendship. *Personal Relationships*, 7(4), 363-378.
- Gray, R. E., Doan, B. D., Shermer, P., Vatter Fitzgerald, A., Berry, M. P., Jenkin, D., et al. (1992). Psychosocial adaptation of survivors of childhood cancer. *Cancer*, 70, 2713-2721.
- Greenberg, H. S., Kazak, A. E., & Meadows, A. T. (1989). Psychological functioning in 8- to 16-year-old cancer survivors and their parents. *Journal of Pediatrics*, 114, 488-493.
- Hatfield, E. (1984). The dangers of intimacy. In V.J. Derlega (Ed.), *Communication, intimacy, and close relationships* (pp. 207-220). New York: Academic Press.
- Hatfield, E., Traupmann, J., Sprecher, S., Utne, M., & Hays, M. (1985). Equity in close relationships. In W. Ickes (Ed.), *Compatible and Incompatible Relationships* (pp. 91-117). New York: Springer-Verlag.
- Hays, D.M., Landsverk, J., Sallan, SE et al. (1992). Educational, occupational, and insurance status of childhood cancer survivors in their fourth and fifth decades of life. *Journal of Clinical Oncology*, 10, 1397-1406.
- Hazan, C., & Shaver, P.R. (1987). Romantic love conceptualized as an attachment process. *Journal of Personality and Social Psychology*, 52, 511-524.

- Henderson, P.A. (1997). Psychosocial adjustment of adult cancer survivors: their needs and counselor interventions. *Journal of Counseling and Development*, 75, 188-194.
- Hendrick, S. (1988). A generic measure of relationship satisfaction. *Journal of Marriage and the Family*, 50, 93-98.
- Herold, A.H., & Roetzheim, R.G. (1992). Cancer survivors. *Cancer Diagnosis and Treatment*, 19, 779-791.
- Hewitt, M., Weiner, S.L., Simone, J.V. (Eds.). (2003). *Childhood cancer survivorship: Improving care and quality of life*. Washington, DC: The National Academies Press.
- Hill, J., Kondryn, H., Mackie, E., McNally, R., & Eden, T. (2003). Adult psychosocial functioning following childhood cancer: the different roles of sons' and daughters' relationships with their fathers and mothers. *Journal of Child Psychology and Psychiatry*, 44(5), 752-762.
- Hill, J. M., & Stuber, M. L. (1997). Long-term adaptation, psychiatric sequelae and PTSD. In J. C. Holland (Ed.), *Psycho-Oncology* (pp. 923-929). Oxford University Press: New York.
- Hobbie, W., Stuber, M. L., Meeske, K., Wissler, K., Rourke, M. T., Ruccione, K., et al. (2000). Symptoms of posttraumatic stress in young adult survivors of childhood cancer. *Journal of Clinical Oncology*, 18(24), 4060-4066.
- Hook, M.K., Gerstein, L.H., Detterich, L., & Gridley, B. (2003). How close are we? Measuring intimacy and examining gender differences. *Journal of Counseling and Development*, 81, 462-472.

- Hudson, M. M., Mertens, A. C., Yasui, Y., Hobbie, W., Chen, H., Gurney, J., G., Yeazel, M., Recklitis, C. J., Marina, N., Robison, L. R., & Oeffinger, K. C. (2003). Health status of adult long-term survivors of childhood cancer. *Journal of the American Medical Association*, 290, 1583-1592.
- Jessor, R., Donovan, J.E., & Costa, F.M. (1991). *Beyond adolescence: Problem behavior and young adult development*. NY: Cambridge University Press.
- Jones, M.E., & Stanton, A.L. (1988). Dysfunctional beliefs, belief similarity, and marital distress: A comparison of models. *Journal of Social and Clinical Psychology*, 7, 1-14.
- Joubert, D., Reza Sadeghi, M., Elliot, M., Devins, G. M., Laperriere, N., & Rodin, G. (2001). Physical sequelae and self-perceived attachment in adult survivors of childhood cancer. *Psycho-oncology*, 10, 284-292.
- Kazak, A. E. (1994). Implications of survival: Pediatric oncology patients and their families. In A. Bearison & R. Mulhern (Eds.), *Pediatric Psychooncology*. New York: Oxford University Press.
- Kazak, A. E., Christakis, D. A., Alderfer, M., & Coiro, M. (1994). Young adolescent cancer survivors and their parents: adjustment, learning problems, and gender. *Journal of Family Psychology*, 8(1), 74-84.
- Kazak, A. E., & Meadows, A. T. (1989). Families of young adolescents who have survived cancer: social-emotional adjustment, adaptability, and social support. *Journal of Pediatric Psychology*, 14(2), 175-191.
- Kazak, A.E. & Stuber, M (1999). The developmental impact of cancer diagnosis and treatment for adolescents. *Trauma and Adolescence, Monograph Series of the International Society of Adolescent Psychiatry*, 1, 143-162.

- Koocher, G. P., & O'Malley, J. E. (1981). *The Damocles syndrome: Psychological consequences of surviving childhood cancer*. New York: McGraw-Hill.
- Kupst, M. J., Natta, M. B., Richardson, C. C., Schulman, J. L., Lavigne, J. V., & Das, L. (1995). Family coping with pediatric leukemia: ten years after treatment. *Journal of Pediatric Psychology*, 20(5), 601-617.
- Langeveld, N.E., Grootenhuis, M.A., Voute, P.A., de Haan, R.J., Van den Bos, C. (2004). Quality of life, self-esteem, and worries in young adult survivors of childhood cancer. *Psycho-oncology*, 13, 867-881.
- Langeveld, N.E., Ubbink, M.C., Last, B.F., Grootenhuis, M.A., Voute, P.A., DeHaan, R.J. (2003). Educational achievement, employment and living situation in long-term young adult survivors of childhood cancer in the Netherlands. *Psycho-oncology*, 12, 213-225.
- Levine, S. (1991). Psychological intimacy. *Journal of Sex and Marital Therapy*, 17(4), 259-267.
- Mackie, E., Hill, J., Kondryn, H., & McNally, R. (2000). Adult psychosocial outcomes in long-term survivors of acute lymphoblastic leukemia and Wilms' tumor: a controlled study. *The Lancet*, 355.
- Maggiolini, A., Grassi, R., Adamoli, L., Corbetta, A., Charmet, G. P., Provantini, K., et al. (2000). Self-image in adolescent survivors of long-term childhood leukemia. *Journal of Pediatric Hematology Oncology*, 22(5), 417-421.
- Masten, A. S. (2001). Ordinary magic: Resilience processes in development. *American Psychologist*, 56(3), 227-238.
- Masten, A. S., Best, K. M., & Garmezy, N. (1990). Resilience and development: Contributions from the study of children who overcome adversity. *Development and Psychopathology*, 2, 425-444.



- Masten, A. S., & Coatsworth, J. D. (1998). The development of competence in favorable and unfavorable environments: Lessons from research on successful children. *American Psychologist*, 53(2), 205-220.
- McAdams, D.P., (1984). Human motives and personal relationships. In V.J. Derlega (Ed.), *Communication, Intimacy, and Close Relationships* (pp. 41-70). New York: Academic.
- McAdams, D.P. & Constantian, C.A. (1983). Intimacy and affiliation motives in daily living: an experience sampling analysis. *Journal of Personality and Social Psychology*, 45, 851-61.
- McAnarney, E.R. (1984). Social maturation: A challenge for handicapped and chronically ill adolescents. *Journal of Adolescent Health Care*, 6(2), 90-101.
- McNulty, J.K., & Karney, B.R. (2004). Positive expectations in the early years of marriage: Should couples expect the best or brace for the worst? *Journal of Personality and Social Psychology*, 86(5), 729-743.
- Meadows, A.T., McKee, L., & Kazak, A.E. (1989). Psychosocial status of young adult survivors of childhood cancer: A survey. *Medical and Pediatric Oncology*, 17, 466-470.
- Miller, J.B., & Hoicowitz, T. (2004). Attachment contexts of adolescent friendship and romance. *Journal of Adolescence*, 27(2), 191-206.
- Miller, R.S. & Lefcourt, H.M. (1982). The assessment of social intimacy. *Journal of Personality Assessment*, 46(5), 514-518.
- Moore, B.D. (2005). Neurocognitive outcomes in survivors of childhood cancer. *Journal of Pediatric Psychology*, 30(1), 51-63.
- Mulhern, R. K., Wasserman, A. L., Friedman, A. G., & Fairclough, D. (1989). Social competence and behavioral adjustment of children who are long-term survivors of cancer. *Pediatrics*, 83(1), 18-25.

- Muris, P., Merckelbach, H., & van Spauwen, I. (2003). The emotional reasoning heuristic in children. *Behaviour Research and Therapy*, 41, 261-272.
- Muris, P., Rapee, R., Meesters, C., Schouten, E., & Geers, M. (2003). Threat perception abnormalities in children: the role of anxiety disorders symptoms, chronic anxiety, and state anxiety. *Anxiety Disorders*, 17, 271-287.
- Newby, W.L., Brown, R.T., Pawletko, T.M., Gold, S. & Whitt, K. 2000. Social skills and psychological adjustment of child and adolescent cancer survivors. *Psycho-oncology*, 9, 113-126.
- Noll, R. B., Bukowski, W. M., Davies, W. H., Koontz, K., & Kulkarni, R. (1993). Adjustment in the peer system of adolescents with cancer: A two-year study. *Journal of Pediatric Psychology*, 18(3), 351-364.
- Norton, R. (1983). Measuring marital quality: A critical look at the dependent variable. *Journal of Marriage and the Family*, 45(1), 141-151.
- Novakovic, B., Fears, T. R., Horowitz, M. E., Tucker, M. A., & Wexler, L. H. (1997). Late effects of therapy in survivors of Ewing's sarcoma family tumors. *Journal of Pediatric Hematology Oncology*, 19(3), 220-225.
- Olson, A. L., Boyle, W. E., Evans, M. W., & Zug, L. A. (1993). Overall function in rural childhood cancer survivors: the role of social competence and emotional health. *Clinical Pediatrics*, 32(334-342).
- Pellegrini, D. S. (1990). Psychosocial risk and protective factors in childhood. *Developmental and Behavioral Pediatrics*, 11, 201-209.
- Pelusi, J. (1997). The lived experience of surviving breast cancer. *Oncology Nursing Forum*, 24, 1343-1353.

- Pendley, J. S., Dahlquist, L. M., & Dreyer, Z. (1997). Body image and psychosocial adjustment in adolescent cancer survivors. *Journal of Pediatric Psychology*, 22(1), 29-42.
- Peterson, L. (1989). Coping by children undergoing stressful medical procedures: some conceptual, methodological, and therapeutic issues. *Journal of Consulting and Clinical Psychology*, 57, 380-387.
- Prager, K.J. (1995). *The psychology of intimacy*. New York: Guilford Press.
- Ptacek, J.T. & Dodge, K.L. (1995). Coping strategies and relationship satisfaction in couples. *Personality and Social Psychology Bulletin*, 21, 76-84.
- Rait, D. S., Ostroff, J. S., Smith, K., Cella, D. F., Tan, C., & Lesko, L. M. (1992). Lives in balance: Perceived family functioning and the psychosocial adjustment of adolescent cancer survivors. *Family Process*, 31, 383-397.
- Rands, M., Levinger, G., & Mellinger, G.D. (1981). Patterns of conflict resolution and marital satisfaction. *Journal of Family Issues*, 2, 297-321.
- Rauck, A.M., Green, D.M., Yasui, Y., Mertens, A., Robison, L.L. (1999). Marriage in the survivors of childhood cancer: A preliminary description from the Childhood Cancer Survivors Study. *Medical and Pediatric Oncology*, 33, 60-63.
- Rauste-von Wright, M. (1989). Body image satisfaction in adolescent girls and boys: A longitudinal study. *Journal of Youth and Adolescence*, 18, 71-83.
- Reis, H.T., & Shaver, P. (1988). Intimacy as an interpersonal process. In S. Duck (ed.) *Handbook of Personal Relationships: Theory, Relationships and Interventions*. Chichester: Wiley.
- Reiter-Purtill, J., & Noll, R.B. (2003). Peer relationships of children with chronic illness. In M.C. Roberts (Ed.), *Handbook of Pediatric Psychology*, 3<sup>rd</sup> ed. (pp. 176-197). New York: Guilford Press.

- Reiter-Purtill, J., Vannatta, K., Gerhardt, C. A., Correll, J., & Noll, R. B. (2003). A controlled longitudinal study of the social functioning of children who completed treatment of cancer. *Journal of Pediatric Hematology Oncology*, 25(6), 467-473.
- Rusbult, C.E. (1980). Commitment and satisfaction in romantic associations: A test of the investment model. *Journal of Experimental Social Psychology*, 16, 172-186.
- Sameroff, A.J., & Seifer, R. (1990). Early contributors to developmental risk. In J. Rolf, A.S. Masten, D. Cicchetti, K.H. Nuechterlein, & S. Weintraub (Eds.), *Risk and protective factors in the development of psychopathology* (pp. 52-66). New York: Cambridge University Press.
- Sanger, M., Copeland, D., & Davidson, E. (1991). Psychosocial adjustment among pediatric cancer patients: a multidimensional assessment. *Journal of Pediatric Psychology*, 16, 463-474.
- Shelby, M.D., Nagle, R.J., Barnett-Queen, L.L., Quattlebaum, P.D., & Wuori, D.F. (1998). Parental reports of psychosocial adjustment and social competence in child survivors of acute lymphocytic leukemia. *Children's Health Care*, 27(2), 113-129.
- Sloper, T., Larcombe, I. J., & Charlton, A. (1994). Psychosocial adjustment of five-year survivors of childhood cancer. *Journal of Cancer Education*, 9, 163-169.
- Spanier, G. (1976). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *Journal of Marriage and the Family*, 38, 15-38.
- Spielberger, C.D. (1972). Anxiety as an emotional state. In C.D. Spielberger (Ed.), *Anxiety: Current trends in theory and research*: Vol. 1. (pp. 23-49). New York: Academic Press.

- Spielberger, C.D., Gorsuch, R.L., Lushene, R., Vagg, P.R., & Jacobs, G.A. (1983). *Manual for the State-Trait Anxiety Inventory (Self-Evaluation Questionnaire)*. Palo Alto, CA: Consulting Psychologists Press.
- Spielberger, C. D., Sydeman, S. J., Owen, A. E., & Marsh, B. J. (1999). Measuring anxiety and anger with the State-Trait Anxiety Inventory (STAI) and the State-Trait Anger Expression Inventory (STAXI). In M.E.Maruish (Ed.), *The Use of Psychological Testing for Treatment Planning and Outcomes Assessment (2nd ed.)*. Washington, D.C.: American Psychological Association.
- Spirito, A., Stark, L.J., Cobiella, C., Drigan, R., Androkites, A., & Hewett, K. (1990). Social adjustment of children successfully treated for cancer. *Journal of Pediatric Psychology*, 15(3), 359-371.
- Spitzber, B.H., Canary, D.J., & Cupach, W.R. (1994). A competence-based approach to the study of interpersonal conflict. In D.D. Cahn (Ed.), *Conflict in personal relationships* (pp. 183-202). Hillsdale, NJ: Lawrence Erlbaum.
- Stam, H., Grootenhuis, M.A., & Last, B.F. (2001). Social and emotional adjustment in young survivors of childhood cancer. *Supportive Care in Cancer*, 9, 489-513.
- Sternberg, R.J. (1997). Construct validation of a triangular love scale. *European Journal of Social Psychology*, 27, 313-335.
- Stuber, M. L., Christakis, D. A., Houskamp, B., & Kazak, A. E. (1996). Posttraumatic symptoms in childhood leukemia survivors and their parents. *Psychosomatics*, 37, 254-261.
- Stuber, M. L., & Kazak, A. E. (1999). The developmental impact of cancer diagnosis and treatment for adolescents. *Trauma and Adolescence: Monograph Series of the International Society for Adolescent Psychiatry*, 1, 143-162.

- Stuber, M. L., Kazak, A. E., Meeske, K., Barakat, L. P., Guthrie, D., Garnier, H., et al. (1997). Predictors of posttraumatic stress symptoms in childhood cancer survivors. *Pediatrics*, *100*(6), 958-964.
- Thaler-DeMers, D. (2001). Intimacy issues: Sexuality, fertility, and relationships. *Seminars in Oncology Nursing*, *17*(4), 255-262.
- Thelen, M.H., Vander Wal, J.S., Muir Thomas, A., & Harmon, R. (2000). Fear of intimacy among dating couples. *Behavior Modification*, *24*(2), 223-240.
- Thibault, J.W., & Kelley, H.H. (1959). *The social psychology of groups*. New York: John Wiley.
- Vance, Y.H., & Eiser, C. (2002). The school experience of the child with cancer. *Child: Care, Health, & Development*, *28*(1), 5-19.
- Van Yperen, N.W., & Buunk, B. (1990). A longitudinal study of equity and satisfaction in intimate relationships. *European Journal of Social Psychology*, *20*, 287-309.
- Wallerstein, J.S. (1989). Children after divorce: Wounds that don't heal. *Perspectives in Psychiatric Care*, *24*(3-4), 107-113.
- Wasserman, A.L., Thompson, E.I., Wilimas, J.A., Fairclough, D.L., et al. (1987). The psychological status of survivors of childhood/adolescent Hodgkin's disease. *American Journal of Disease in Childhood*, *141*, 626-631.
- Weigers, M.E., Chelser, M.A., Zebrack, B.J., & Goldman, S. (1998). Self-reported worries among long-term survivors of childhood cancer and their peers. *Journal of Psychosocial Oncology*, *16*, 1-24.
- Winstead, B.A., Derlega, V.J., & Rose, S. (1997). *Gender and close relationships*. Thousand Oaks, CA: Sage Publications.

- Woodgate, R. L. (1999). Social support in children with cancer: A review of the literature. *Journal of Pediatric Oncology Nursing, 16*(4), 201-213.
- Zebrack, B.J., & Chesler, M.A. (2002). Quality of life in childhood cancer survivors. *Psycho-oncology, 11*, 132-141.
- Zebrack, B. J., Zeltzer, L. K., Whitton, J., Mertens, A. C., Odom, L., Berkow, R., et al. (2002). Psychological outcome in long-term survivors of childhood leukemia, Hodgkin's disease, and Non-Hodgkin's lymphoma: A report from the childhood cancer survivor study. *Pediatrics, 110*, 42-52.
- Zeltzer, L.K. (1993). Cancer in adolescents and young adults: psychosocial aspects. *Cancer, 71*, 3463-3468.
- Zeltzer, L. K., Chen, E., Weiss, R., Guo, M. D., Robison, L. L., Meadows, A. T., et al. (1997). Comparison of psychologic outcome in adult survivors of childhood acute lymphoblastic leukemia versus sibling controls: A Cooperative Children's Cancer Group and National Institutes of Health Study. *Journal of Clinical Oncology, 15*, 547-556.

## **APPENDIX A: Qualitative Interview Conversational Guide**

1. Ideally, what makes a good relationship? What do you look for in a partner? What are your expectations for your partner?
2. Tell me about your current relationship.
3. Tell me about your past relationships.
4. How much do you confide in your partners?

(Questions were asked a second time with regard to close, same-sex friendships).

5. How do you feel your early experience with childhood cancer has affected your romantic and friendship relationships?



## **APPENDIX B: Qualitative Interview Transcript Text**

### **Maturity and Perspective**

1. Survivor: "I'm a little bit more independent. And more religious too. Since then, I got a lot closer to God and that's something that's kinda more important to me. I do like being a lone a lot and praying, ya know."

2. Survivor: "I feel like had I not experienced that I think I would have been a completely different person. I think it was incredibly humbling cause in addition to that being an awkward time in your life I think that's also a time in your life when egos start to develop. And I'm not gonna lie, I think I definitely would have had a big one. I had a lot of friends; I was an athlete, a good student, involved in nearly everything. I think it would have been rather easy for me to become stuck up and sort of develop an ego...but that's a completely different personality than I have now. And I think in a way it made me a little more standoffish-- at first, of course cause that's not something that's going to increase your confidence. But in the long-run, I think it definitely, it makes you look at people in a whole different light. After seeing all the children going through this, every type of individual, and just the way that people deal with it and how strong people are when they deal it. And this is something someone in every walk of life goes through and people all deal with it in different ways but somehow you have no choice, you have to. So I think it makes you see different people and makes you find some common ground with them and I think that is something I definitely learned. That you can find a sort of common ground with everyone. Even if you dislike that person or your personalities are completely different, there is always a reason to be kind to them."

3. Survivor: "I wouldn't take it back cause it kinda shapes who you are. And I learned a lot from it. It shapes who you are and how you deal with things. Oh, this is life. And it's helped a lot in understanding people, in considering that they may be going through their tough time."

4. Survivor: "I think it helped me as a person develop my personality—from going through a lot with my family, and friends, dealing with some many situations, I kinda became more

confident and more aware of what I was like as a person, what I was able to handle, learned ways to cope, to gain some perspective. I value health very much, being healthy- I still had some residual problems from the cancer, so I think I appreciate my health a lot more than others do. And I think other things don't bother me quite as much; I'm happy when I'm physically capable. It keeps me grounded.

5. Survivor: "A lot of things I noticed, I noticed this a lot in high school and I'm surprised to notice it in college, like I said, little things get to people, or people crying and making a really big deal over something that happened, and I'll hear what it is and I'll be like, oh my gosh are you kidding me? and I won't say that but I'll think that in my head and I think that's another reason why I don't have that many close friends cause a lot of times I feel, like, almost more mature than people. A lot of times I don't feel like I'm on the same page as people when there telling me about the things that are bothering them or they're going through. I kinda feel, I mean I'm a nice person, compassionate, but I kinda feel, in a way, fake cause I'm thinking in my head, its really not that big of a deal, its really not the end of the world, but to them it is and I wouldn't expect them to understand that unless they went through something."

## **Self-Disclosure**

### **Of Cancer History**

1. Survivor: "It's never something I hide from anyone I've ever gone out with. Usually a situation where they'll be talking about somebody they know that has it and I'll say, "yeah I was really sick to, I had a form of it when I was younger". It's funny, though, most every, no every person I've ever had a romantic relationship, none of them have ever wanted to talk about it; they don't want details, don't want to know anything about it. I don't know. If the pages were turned and somebody I was with said that to me, I would want to know a lot of details—what happened, what it was like, what kinda things they went through, but I don't know why. I've always kinda said to myself that I'll know, I don't know why I put this much importance on it, but I always say to myself that if someone is really truly gonna be around for a long time cause they'll ask questions and want to know about it and so far I haven't met anyone like that. It's like they don't care almost and don't want to know about it. It's hard because I don't think most people understand how much it truly impacts your life and how it complete changes you as a person—

there's you before that and you after that. It kinda separates your life into two and people don't realize how much of an impact it is and how much importance it plays and so you almost want to talk about it and tell people about it and answer people's questions. Some people do ask a lot of questions about it but as far as romantic relationships, nobody ever has. It's hard. I don't know I don't push the issue cause I don't really understand it."

2. Interviewer: "You said you've been skeptical to tell partners about your cancer?"

Survivor: "Yeah. I was in a relationship for a year and a half and I had never even told him about that. I don't know, I guess before I had cancer, just hearing the word just scared me—that's people's naturally reactions—and I just, I don't know if its that I don't want people to be sympathetic, or, I just don't think people fully understand that that doesn't make you bad or different or unhealthy or whatever and I think a lot of people that's their initial reactions. I don't know, I guess I'm afraid to tell people even in my regular friendships, I feel the same way."

Interviewer: "What do you think you're afraid of?"

Survivor: "I'm not really sure. I'm thinking the way they would act toward me. I don't know, maybe its cause its something that's still on my mind after so long, that I think that would be in the back of their minds and it's not something I want someone to focus on about me.

For a while, I never really wanted to talk to anyone about it, even when I was going through my treatment. I was 11. You know, like my parents and stuff, I just really liked to kinda act like it wasn't happening. There was really no one I confided in during that time, so even the years after it, someone would bring something up to me about it, and I'd start crying and not even be able to talk about it, and not want to. So, I think, I'd say around 11<sup>th</sup> grade, two years into high school, was finally the point where I had kind of became comfortable talking about it, whether it be writing a paper about it or discussing it with an adult, that was really the first time I was comfortable enough to talking about it. And that was really my first close relationship with someone, long-term relationship, you know the year and a half relationship, and I was just nervous that if he looked at it the wrong way then that would ruin things early and I just didn't want THAT to be the thing that ruined it.

Interviewer: "So you never really wanted to talk about it?"

Survivor: "No. I'd have to say I was trying to protect the other people in my life. I mean, I felt like for my age I dealt with it pretty well and I just thought I guess if I talked to other

people about it, I'd kinda be burdening them with my problems. Like my parents and stuff, I felt bad that they even had to go through it with me, that I felt like if I was constantly talking to them about it, opening up, telling them my fears and everything, that they would become more aware of that. And I don't know I thought that I could keep going and handle it myself and I didn't want to have to burden other people. Sometimes it was just easier to keep it all in."

3. Survivor: "While I was going through it, I never talked to any of my friends about it at all. And even after the fact, people that I was friends with throughout junior high and high school, I mean some people knew about it, but never did I really talk to any of my friends about it, until, I'd say, two years ago, my senior year was the first time I actually ever talk to one of my friends about it at all. I don't know, I feel like I have a pretty strong personality and I feel like when I meet people and talk with them, people pick up on that and I just think that people will really look at that as a weakness and that's why that's one thing I kinda like to hide unless I can explain to them the whole story.

It was really, I mean I still kept to the same friends, but I really just acted like I wasn't going through it, I didn't talk to them about it all. I mean if it wasn't for the whole physical side effects a lot of people probably wouldn't have known I was going through it. No one really ever questioned me about things. It was more or less, like me sitting in class and hearing someone behind me saying, oh, looks like Jenny lost more hair. More or less comments that people didn't try to make me hear but that I did overhear. Never any questions were asked but the little comments I overheard I guess affected me."

4. Survivor: "There never really seems to be a good time to bring it up. I'm always skeptical about telling people but it almost seems like after I do, it's a relief, it's almost like therapy for me, being able to talk about it. Cause I guess one of the things I regret is not talking about it more during that time period cause I think keeping it in affected me so now whenever I'm able to talk about it, I feel like I'm finally beginning to reach some closure on it. Whenever I do talk to people about it, people never really have much to say, are kinda taken back by it."

5. Survivor: "I'm always afraid and unsure of how people are going to react. And especially then, I never wanted to tell anybody, just wasn't comfortable, didn't want people to think of me

differently. I just don't want people to feel sorry for me. I just don't think it's that big of a deal. Its just something my life threw at me and I had to deal with going through treatment and having surgery and I think if anybody was put in the situation, they would have done the same thing and I don't want people to like feel bad for me cause that happened and I don't want them to look at me different. No one's really done that but I'm just afraid that's gonna be the case. But its definitely becoming more easy for me to tell people about it. I think just seeing that more people just don't care has helped."

6. Survivor: "When I told my best friend, I felt more comfortable about what had gone on. It was easier, it wasn't awkward, she asked a lot more questions which was something I hadn't previously encountered and even after we've known each other for four years, she still asks questions...about different things, certain medicines I'm on and stuff. It was hard in one sense but it was also kind of a relief that someone finally cared, they just didn't kinda blow it off like oh, that's too bad, my great grandfather died of cancer—like that's the same thing. Her eyes never looked away from mine, I remember that very clearly, she wasn't preoccupied with anything else, her focus was directly on that, wanting to know more and more. It was hard at some points cause it made it such a reality to me. Certain things that I didn't even know I remembered, for the first time in years and years, someone was asking me to recall that, like 'what do you remember? What was it like? What did it smell like?' things like that. Made it really vivid.

Interviewer: "So you felt more comfortable telling her than you do telling a potential boyfriend?"

Survivor: "Yeah. I think I felt like I didn't really have to impress her. I feel like there are so few guys for me to pick from, that are attracted to me that I'm attracted to, that its like, this could easily be the deal-breaker that scares them away. My mom has warned me about that, watch that information cause that's scary to some people."

7. Interviewer: "You've been surprised by people's reactions?"

Survivor: "Yeah. No one ever brings it up. Including family members. It's just never brought up and never discussed. I don't know if its because people think I would be upset by it or if other people don't think about it, but I still think about it. Its been over 15 years but I still

think about it and its just surprising that its never brought up. Sometimes I'll ask my parents about things, and I think, it was a whole experience for them as well, so as much as I was going through, I'm sure they were going through just as much. So to have them ask me, well how did you feel? While they were feeling 10x worse. That doesn't really surprise me cause we were all going through it together. But when I hear about other people going through things, I want to ask questions and find out more. "

8. Survivor: "In school, I don't really remember anyone being distant, but I think they were afraid. I would always have to sit by myself. Everyone would kinda sit away or look at me weird. After like third grade, no one really remembered anymore or cared. I didn't want to use it as an excuse so I wouldn't bring it up or would just let it drop. And by high school, no one really knew at all. I usually just tell my close friends. A lot of times it came up more cause I was telling them about the Hep C, not the cancer. It takes a while for me to tell anybody. I worry about being pitied. I don't want special attention, just want to be able to do what I want to do."

### **Of Emotions and Personal Thoughts**

1. Survivor: "I think I do kinda keep a wall up sometimes, especially with someone that might be getting close cause when I did get sick everybody left and I still think that's a fear of mine—that everybody's going to leave me—so I feel like I have to cope on my own. But you know, eventually, I end up giving too much, going the other way.

Interviewer: "Everybody left?"

Survivor: "When I got sick, I had five or six really good friends and that was the end of it. They didn't visit, wouldn't call, wouldn't talk to me. And the rest of my family too. It was just me and my mom and my dad. I had like one other aunt that was there but everybody else just ignored it, it wasn't talked about. It was horrible. It would have been nice, well see I did have one friend but we didn't talk about it. I would have liked to have somebody to talk about it instead of worry at night. My mom became my best friend.

I think about my friend Jessica, I known that she was there but we weren't really as close. I don't think she ever came to visit but I know we did write a lot. My friend Erin would come visit me at the hospital and try to cheer me up but after I got better and I went back to school, I was like invisible. I didn't fit in to the rest of her group. We were just friends cause I was sick, I

guess. We were all still in the same high school and they didn't have anything to do with me. And I tried, believe me I tried, I tried so hard. And I lost all my hair and I blew up then I lost weight and I didn't like myself at all and didn't want anybody to see me. But I would have liked to have somebody. Now I'll keep everything bottled up but when I get to where I really wanna talk about it and there's no one there so I'll just bottle it up again."

2. Survivor: "I'm kinda an introvert when it comes to thoughts, feelings, things that I want—I find it hard to talk about cause its always been fend for yourself. Like my whole childhood, it was 'well we're not going to escalate this cause I don't want people to over exaggerate. Like when I had cancer, my mom took it hard, and I didn't want to over escalate anything; like if it hurt a lot, I kinda just dealed. Like you're given it, deal with it. And I guess that's escalated into now, where if I feel something, I deal with it. Not 'well, I feel this, We'll deal with it'. I never really thought about it cause its just something I do. Everybody has their downfalls and that's what I'd consider mine. Why can't I just say what's wrong? And I think this is how I deal with it cause then I'm in control and I don't have to worry about someone else getting hurt or someone else worrying. I guess I don't want others to worry about me.

I remember when I went through things, like a spinal tap, my mom wouldn't come in the room, would sit in the hall and cry. For me it just was what it was. Something you deal with. You're given whatever and you deal with it. But for her, it was something she had to see me deal with. And I didn't want to make it harder for her—so I was like, 'if I can help out in this way; I'll just deal with it'. I figured with all that was going on, if I could deal with this one thing, I could take that one thing off their minds."

3. Survivor: "I actually keep things to myself a lot. He's always saying he has to pry information from me cause I don't like to be upset in front of other people. I'm always afraid they're gonna be too worried and spend too much time focusing on me and not on something they should be doing. I guess maybe it came from when I was sick cause I'd see my parents worried all the time and I was the one they were worried about. It has caused some conflict, but it has gotten better. He realizes I will tell him eventually; I just need to know he's not going to freak out if I'm upset."

## **Body Image**

1. Survivor: "Body image. It still is a big thing for me and it was a big thing for me then. Its hard to say cause your body is changing so much at that time anyway. I really don't know how I would view myself now if I hadn't gotten cancer, if my body hadn't gone through the changes that it went through. My skin tone changed a lot. I was pretty dark complected. Like I said, it's hard for me to know—I don't know, maybe it stunted my growth. Maybe I would weigh 20 lbs less- cause I did gain a lot of weight from the steroids. And I have stretch marks, but its possible I could have gotten those anyway. And I have a few scars. But I think, that's, well people say you have to be able to love yourself before you can love someone else, and its not that I don't, but as far as body image, I definitely have some confidence issues and that does affect your relationships. It hasn't been anything that has caused my relationships to fail or hasn't had that big an impact, but I think it definitely affects how close you can get to someone. And it may just take a longer time for you to get closer to them or, I don't know, I just think it has an effect. There's a lingering self-consciousness that comes with the territory. And for me, more in the physical sense. Emotionally, like I said, I don't really have anything to hide and I'm not ashamed of the way I feel about anything. But physically, I think it may take me a little bit longer than other people to get into that intimate relationship. And its great when it happens but in terms of my self-confidence, it prolongs that part of the relationship. And that might be a good thing.

Interviewer: "What do you think you're worried about?"

Survivor: "Oh my goodness. My fear? Not embarrassment, not the right word at all. Its not that I don't find myself attractive. I think it just really comes down to self-confidence. If you are someone, and I am, as far as my body goes, like I said I was an athlete and in relatively good shape, but I'm sort of a perfectionistic. And if you yourself can't look at you body and be satisfied then its kinda hard to allow someone else to look at it and expect them to be satisfied or them to look at it in a, oh, she's perfect in my eyes, which is what every girl wants. If you're picking things out on your body that you don't like, you have a tendency to think that other people are all doing the same thing."

2. Survivor: "I guess there are things I hold in. I have a lot of health problems from my chemo, just side effects and stuff, and I get very self-conscious about it. There are things that I



don't tell people and things I didn't tell my husband at first that I probably should have. It was maybe a year or two until I told him about some of the health problems I have because it's something I don't like to talk about, so I don't like to bring attention to it. I guess it makes me more self-conscious like I feel like, well if they don't know about it, then maybe they don't notice it cause I'm always worried 'well do people notice that I have like...like I had to get bridges cause my teeth never developed so I have like false teeth so I think that if I don't tell people then they don't know. Stuff like that like I don't like to bring attention to it so I hold it in but it's just something I probably just tell people like my husband but I figure well, if he doesn't notice, then maybe I don't have to tell him.

It's (side effects) something that I have to live with now and I have a lot of problems with my back and most of it is cosmetic and I worry that how I look people will notice that I'm different and that I walk differently cause of the muscles in my legs. I don't like people to notice it so if they don't mention it, I don't. A lot of it is I need my significant other's approval. I'm very self-conscious about things just because of the physical...like the side effects from that and I get very upset if my husband or anyone I have dated would say anything remotely close to something and they didn't mean it to be mean, but I'm very sensitive about certain things and that has caused fights or rifts in our relationship. And I know that it's me cause I'm just very self-conscious about things. To a normal person the comments would be nothing, but to me, I'm very sensitive about things and it has caused conflict in all my relationships at one time or another.

And I think it has gotten worse as I got older. I think during teenage years it was pretty bad, just cause high school/ middle school is hard for anyone. College it probably wasn't so bad; didn't really seem to play a big role, wasn't a problem. Now, sometimes it's a bigger problem, almost maybe gotten a little worse. It's not as bad as it was in adolescence. But I don't know why. Maybe part of it is because my relationship with my husband is the most important relationship I've ever had so everything is magnified, maybe cause this relationship is so important to me, cause I need his approval a lot more than anyone else I'd ever dated.

I think people don't react to me any different, I think it's all me, like I'm always thinking, 'oh what are they thinking'. I honestly don't think that they react any differently to me than they would to any other person. But to me, and I say a lot of time, I get upset because I don't feel normal sometimes and that's why, it causes me to become upset when I'm really a normal person

but certain things with my health make me feel like I'm not a normal person all the time and then that spills over then into the relationship. That's when I start feeling self-conscious and I worry about things. I don't think it was ever so bad it caused any other person or me to say this is too hard I can't do this. We've pretty much always worked through it. It would pretty much be little arguments and then we'd get over it I guess and try move on.

I can tell my friends, I tell them everything. And I never have really held anything in, its never been a problem for me. My husband tells me I tell them too much about my life. I don't know if its because they're girls and I feel more comfortable and I can talk about anything. There's something different there and I don't know if its because no matter what I look like, what happens to me, my friends aren't gonna...I don't know if its because I need my husband to think I'm attractive, I don't really need that from my friends, I just need them to be my friends. I do like to get my friends approval but I don't need it's as much as a need for me cause I know that the close friends I have, maybe at one time in middle school when I was making friends, I needed their approval, but once I had my friends and we had our group, I felt like they were gonna be my friends no matter what.

### **Trust**

1. Interviewer: "Are you currently in a relationship?"

Survivor: "No. The one actually defined on both sides when we were actually in a solid relationship was about five years ago. We were together for 8 months. I can easily see where if both met and fell short of my expectations. I felt like I could trust him and for the greater part of our relationship I did. But that's also where it fell apart at the end. He wasn't being as honest with me. He wasn't affectionate with me. He didn't want to stand to close or get to close and I never really got to the root of why that was and I have experienced the same thing in later relationships so I'm beginning to think it's not them. I think that I come across sometimes as ambivalent. I want to be close but I don't feel that I, I don't know if it's that I don't trust them enough, I think I'm afraid of being too close. And I think that's something that displays itself outward. And something that I know was not just there but in other relationships, even my girlfriends that I live with have commented on the same thing. It's like a physical proximity issue. Physically, I'm torn. I want to be close but are they gonna do something I cant stop, like are they gonna go too far or are they physically gonna take control of me where I can't

fend for myself. And that stuff crosses my mind even with close friends that I trust, I don't feel comfortable, I feel very on edge, ready to defend myself at any time, like I can't concentrate on, can't be in the moment, even though I've tried. But I think too, emotionally, I don't know the emotional bounds. I don't know what is too close and what is too far so I bounce between the two—like on the second date divulging a lot of information but then not telling them other things that are like normal occurrences or everyday fears.”

Interviewer: “Where do you think that comes from?”

Survivor: “I don't remember so much from when I was sick, but there are some distinct flash memories and those are what has impacted me the most. Most of my doctors were male, they were the ones who did the surgery, started the chemo drips, took the blood. I would always cry when I went into the office cause I knew what was coming. So I think that is something, because there was that physical hurt-- I was very close with them because I did trust them, I knew they knew what was best, they were very personable and I was close with them, but they had physically hurt me. I think that is still where some of my hesitancy has come from, where I let myself go and then pull back, let myself go and pull back. And I know clearly it wasn't to hurt me hurt me but I do remember sitting on the table and that it was my male doctors that had stuck me. And I think that's why I have a harder time trusting males. And my mom was the one who took me to all my treatments, sat with me in the hospital, so I think too that's where the respect for family comes from. My dad wasn't there, he was out working to pay for the medical bills, but he wasn't there too and it was like he would leave when it got tough. And whether it was intentional or not my mom was there night and day and slept there and my dad was the one who came and went.”

### **Fertility**

1. Survivor: “I definitely think about that cause cancer is one thing that happened, but I also have arthritis and a thyroid problem, and I have some problems that occurred kind of as complications and none of them are anything that are physically debilitating or obvious to anyone else, but there are other health things that I have wrong now and I am kind of afraid cause I kind of feel that I have a weakened immune system and that something about my body is

not quite up to par. And I do get nervous that if I do have kids there might be something wrong with them and it would be because of me.”

2. Survivor: “I think I’m more worried if I’m gonna be able to have kids or not. Cause when I was going through it, I didn’t want to hear anything about statistics or anything like that so I don’t know what the after effects, long-term effects of my drugs are. And I guess I’ve kinda thought about that, but not something that would ever stop me from trying. There’s a chance that anything could go wrong, ya know?”

3. Survivor: “That is something that has always been a fear since I started puberty. For a long time I didn’t want kids, I didn’t want to get married—they’re going to disappoint me in the end, so why bother? But now I do want to have kids. The fear I have is that the cancer that I had is genetic. So there’s a good chance that they would have it. I was also told this fall that there’s a strong likelihood I’m infertile due to the chemo treatment and that was devastating. I’ve had irregular periods since I started puberty and it got to the point that the pill doesn’t work and they figured that since I had cancer maybe they shouldn’t just blow that off. They did a sonogram and everything is intact but at the same time, the cancer did hit at a prime growth period and all the treatment was targeted to my pelvis that they said my hormones aren’t going to be regular and chances are it has destroyed my eggs. And that was, by far, the most devastating month of my life, trying to cope with that. But I think now, because of that, it has made me even more open to having a child who is either mentally or physically disabled or to adopt one. Having a child that’s different cause I know that I was different too. God has prepared me to be able to understand and welcome and love that child.”

4. Survivor: “We do want to have kids, not for a couple years, but...I’d like to have two or three kids but we’ll see. And part of me, you know, I do worry sometimes about the health aspects, and its hard but then I think, well if its meant to be, then. Cause I don’t know, I have a lot of back problems because of my radiation that was right in my pelvic area. So I wonder how am I gonna be pregnant when my back hurts all the time now. I worry about that kind stuff. And I worry, oh no, cancer is hereditary sometimes, like what if my children, I would feel like I was the one who gave it to them...and I probably should talk to my husband about it but I don’t think

I ever have. I mean we talk about it a little bit and he says are you worried that maybe you won't be able to get pregnant and I say I don't know cause the doctor's never told me I couldn't. They never told me otherwise so I would assume if there was a problem they would have let me know. Its almost like I don't talk about it so it won't become an issue; if I don't talk about it, it won't happen."

### **Other**

**Interviewer: "How do you feel your early experiences with childhood cancer may have affected your romantic relationships today?"**

1. Survivor: "Well, like mostly the only thing we argue about, is something to do with me, the way that I act, my attitude. He gets mad and says that I have a very negative view on life; he thinks I'm a very pessimistic person, he's more an upbeat kinda person and it really gets to him that I'm so cynical.

Interviewer: "So cynical?"

Survivor: "Yeah and I think that comes from what I went through. I don't know, one thing always sticks in my head, when I first found out and I remember being 13 at Children's, I remember them telling my parents in front of me, that approximately 1 in 200,000 kids get what I got. And I remember thinking that 1 in 200,000 and it had to be me and why couldn't I have just one the lottery instead; if its gonna be that kinda odds, why would this happen. And I think I kinda carry that view in life, like if its gonna happen to somebody, its gonna happen to me. I don't know, its just something I think can make you a really positive, upbeat person like it does for some people, or it can make you really kinda, break you down and make you more cynical.

I don't think this sounds very good, but I think it has affected my relationships, at least, negatively because I think that because I was put through that and it was such a bad experience, I think you almost start to think you deserve to live like that. So I think I've been willing to put up with far more from the people I've gone out with than most girls would have because, I don't know what you want to call it, learned helplessness maybe?"

2. Survivor: "From a positive aspect, I think going through that has made me realize that a lot of the petty things that maybe people in relationships do and generally get in little arguments or bigger about, I realize are really not that big of a deal and so not really too much bothers me in

relationships cause it has put things into perspective. So on a positive end, it has given me a better perspective on things, and better apt to deal with things like that. But negatively, I do feel like because I went through that, that I do have to, at some point tell my partner about it, and I guess like, once I found that he like accepted that, that I was so happy with that that I kind of overlooked some other aspects of our relationship that bothered me, certain things he was doing, certain things he'll say. That generally if that happened, I'd say it's over but because I feel like he accepted me on that level, that I should kinda overlook those things. And I realize I'm doing it but I don't know why. I understand it shouldn't be a negative thing that I went through that but I just really have a fear that people will take it that way, so I kinda feel like if I have a person I've opened up to and he's accepted that that I should hold on to.

3. Survivor: "I had some really bad past relationships. About six years ago I was in a very abusive relationship and it took me a while to realize that I could stand up for myself and that it didn't matter if I was sick or weak before, I didn't have to take it. And then, I was in verbally abusive relationship—I realized I was settling.

Interviewer: "Sick and weak?"

Survivor: "I guess its from my family, cause my mom and dad are always worried about me. Oh, you're sick, you're the weak one, you stay home, we'll take care of you, just do what we say and everything will be okay. I'm used to just listening to what other people are saying and taking it. But now I realize I don't need to take it and I don't need to rely on other people.

Interviewer: "So how would you say that cancer may have affected your romantic relationships?"

Survivor: "Negatively, it taught me, I don't know, that I needed to depend on someone and that people never told me the truth. They were always like, well, your sick but they wouldn't tell me how sick so I always learning not to trust people about what they were saying."

**Interviewer: "How do you feel your early experiences with childhood cancer may have affected your romantic relationships today?"**

1. Survivor: "That to me, was probably the worse part. I had just started a new school and we were only 4 months into the school year and I had made several friends I really liked a lot and

had a big circle of friends and was dating somebody and for the first time I felt really good, like I had a big social group and then I kinda got yanked out when everything happened. It seems to me that one or two girls really did try to visit me in the hospital that first or second week. The one girl wrote cards to me and came to my house to visit me, but that only lasted for maybe 2 months if that and then, well that was hard for me cause they all went back and kinda went with their group and I was kinda out of the picture. And when I returned back to school I was definitely out of the picture. It's like they tried but it was too much I think and I don't blame that for that. Other kids at school were mean. I wore a wig and I thought it was pretty natural but I would hear people making comments about it and one kid who sat behind me tried to pull it off. I used to come home and cry and cry and cry. I'd put on a tough face at school. College was much better though. I don't think I really value friendship as much and I know it has a lot to do with high school cause I remember thinking if these girls were really friends they would have tried longer, would have welcomed me back into school. I know I have a negative view on that like cause they say they're your friend but are they really gonna be there through thick and thin?"

2. Survivor: "I don't know, I have a hard time getting close to people. I have a couple of close friends but not one I would consider my best friend. I don't know if its cause I feel like I'm holding back by not saying that, but ever since that happened, I mean I've always had close friends, but I remember when I was younger I always had a best friend and I still notice in college a lot of people have their one best friends and for I while I haven't really had that and I don't know if that has anything to do with it or not but sometimes I feel like it does. My current boyfriend and my last boyfriend have both said that I'm hard to get to know."

3. Survivor: "I think that it, I said this before, initially it did make me shy for a while, more than I was beforehand but then I think it allowed me to get closer. It changes your outlook and makes you think that life is short and anything could happen and you want the people you really love in your life and you wanna spend time with them and get close to them. I don't feel I get as close to them as they get to me, but I still think that I want them to feel like they're close to me. Negatively, I guess just the opposite, the fact that I don't really...I guess some of my shyness or the desire to keep things a little more personal, maybe that's something that stuck with me.

4. Survivor: “Well, at the time, after remission when I was about 6, I remember going to kindergarten, first and second grade, I let myself be trampled on, I never stood up for myself, I just let myself be walked all over, that was kinda how I made friends, I just did anything they told me to. I wasn’t really ever around kids who weren’t sick. I was always around kids who were different too. I really didn’t really know how to be accepted, to interact with anyone but adults. The hardest years were from fourth grade on, my separation anxiety was beyond out of control. I cried every night, every morning, kicked and screamed to get into the car, throwing up, leaving my mom. I couldn’t even do sleep overs until I started freshman year of college. I couldn’t deal with being away from her or if she was there I didn’t want to associate with anyone else. I just wanted to be with her, that was my safe zone. Between throwing up in the middle of the night, it was easier to keep me in the same room with her. So when I had to go out into the world, I had a very difficult time interacting with anyone my own age until the later years of high school. Even into college, I was much more comfortable talking to adult populations than kids my own age.”

5. Survivor: “It has, especially with girls, I know that once I find someone who is a really good friend, I have a very difficult time ever letting them go. Like I don’t want to be separate from them. We’re exclusive, very close, very deep, but I have just very tight one-on-one relationships. Both my friends are older than me. My best friend is two years older. She thinks I’m more mature than she is. I form deep, girl relationships—just a very few. I see that as a good thing cause its someone I can really turn to, I can really trust. Plus they act as a good liaison for meeting other people in the real world. I can open up more and trust them more than a romantic partner. I’m not as scared of a girl leaving and walking out of my life as I am with a guy. I consider it almost inevitable that a man will disappoint me and leave. A girl, I don’t expect that as much from them and I feel too that I can tolerate a lot more from a girl in terms of personality, and idiosyncrasies, and arguments.”

6. Survivor: “Well, since I was one the floor with a lot of little kids, I think I was more able to understand other kids with problems. I was less likely to make fun of others and more likely to be friends with those that no body else wanted to be friends with. Negatively, seeing kids come and go and a lot of them not coming back—and subconsciously I knew why but nobody



would ever say it out loud—so sometimes I was like, if I’m gonna be friend’s with this person, are they not going to come back.”

## APPENDIX C: Tables

**Table 1 Survivor Illness and Treatment Variables**

**n = 60**

	%	n	Mean
Diagnoses			
ALL	36.6%	22	
Hodgkin's Lymphoma	10.0%	6	
NonHodgkin's Lymphoma	10.0%	6	
Wilm's Tumor	8.3%	5	
Ewing's Sarcoma	8.3%	4	
Rhabdomyosarcoma	5.0%	3	
Neuroblastoma	5.0%	3	
Osteogenic Sarcoma	3.3%	2	
Other	15.0%	9	
Age of Diagnosis			8.06 years (range 1-17)
0-5	38.3%	23	
6-11	28.3%	17	
12 and over	33.3%	20	
Time off Treatment			12.73 years (range 3-22)
Treatment Intensity			
Mild	9.3%	5	
Moderate	47.2%	26	
Severe	43.4%	24	

**Table 2 Sample Demographics****N = 120**

	Survivors (mean or %)	Controls (mean or %)
Age	M = 21.61	M = 20.05**
Gender		
Male	32.2%	34.4%
Female	67.8%	65.6%
Ethnicity		
White/Caucasian	93.2%	85.2%
Minority	6.8%	14.8%
Education		
High school	22.0%	34.4%
Some College or Post High School Training	45.8%	47.6%
College Degree	28.8%	14.8%
Graduate/Professional Degree	3.4%	3.3%
Marital Status		
Single	84.7%	95.1%
Unmarried, but living with a partner	8.5%	3.3%
Married	5.1%	0%
Divorced	1.7%	1.6%
Have Children	5.1%	1.6%

	Survivors (mean or %)	Controls (mean or %)
Mother's Education		
High school	42.4%	32.7%
Post high school/ college Training	44.1%	47.5%
Graduate/Professional Degree	11.9%	19.6%
Father's Education		
High school	42.4%	31.1%
Post high school/college training	35.6%	34.4%
Graduate/Professional Degree	16.9%	29.5%
Parents' Marital Status		
Single	5.1%	1.6%
Married	81.4%	77.0%
Divorced	3.4%	16.4%
Widowed	8.5%	1.6%
N	60	60

**Table 3 Descriptive Statistics for Study Measures**

	Mean	SD	Min	Max	Internal Consistency (Cronbach's Alpha)
Romantic Relationships					
Relationship Assessment Scale	28.73	4.92	11.00	35.00	.90
Expectations	39.76	7.10	20.00	52.00	.75
Miller Social Intimacy Scale	148.01	20.36	75.00	239.00	.84
Fear of Intimacy Scale	74.28	17.99	50.00	128.00	.88
Friendships					
Relationship Assessment Scale	30.70	4.07	16.00	35.00	.81
Expectations	35.24	5.96	19.00	45.00	.81
Miller Social Intimacy Scale	129.66	23.96	44.00	167.00	.83
Fear of Intimacy Scale	67.74	14.48	40.00	103.00	.86
State-Trait Anxiety Inventory--	46.76	4.27	37.00	58.00	.90
Trait Anxiety Subscale					

**Table 4 Group Differences for Romantic Relationship Variables****N= 120**

	Survivors	Controls	Odd's Ratio	Cohen's d	p value
Ever been in a relationship	89.5%	92.3%	.71		.44
Ever been married	7.1%	1.5%	4.92		.12
Ever lived with a partner	7.1%	4.6%	1.60		.62
Currently in a relationship	52.6%	70.8%	.46		.01**
Number of relationships in last 5 years	1.77	2.29		.45	.01**
Average length of relationships (mos)	22.48	15.97		.52	.35
Average level of conflict	2.40	2.57		.17	.42
Average level of distress over break-up	3.41	2.79		.60	.03*
Relationship Satisfaction	27.46	28.28		.15	.43
Relationship Expectations	38.53	39.20		.08	.63
Intimacy	141.76	146.58		.21	.42
Fear of Intimacy	80.00	76.37		.18	.33

*Note.* All analyses controlled for age. Cohen's ds are calculated using the SD of the control group.

**Table 5 Correlation Matrix of Romantic Relationship Variables**

	1	2	3	4	5	6	7	8	9
1. Age	-	-.058	.37**	-.18*	-.00	-.02	-.09	.01	-.03
2. Gender		-	-.07	.11	.10	.22*	.02	.10	-.06
3. Childhood Cancer Status			-	-.11	-.07	-.05	-.10	.09	-.22*
4. Trait Anxiety				-	-.12	-.01	-.04	.09	.10
5. Relationship Satisfaction					-	.68**	.68**	-.58**	.06
6. Expectations						-	.56**	.50**	.20
7. Intimacy							-	-.64**	.08
8. Fear of Intimacy								-	-.03
9. Number of Relationships in the last five years									-

\* p = .05; \*\* p &lt; .01

**Table 6 Moderation of Childhood Illness Group and Romantic Relationship Satisfaction**  
**N = 119**

	$\beta$ (p)
<hr/> Model 1 <hr/>	
Step 1	
Age	-.02 (.83)
Trait Anxiety	-.12 (.22)
Step 2	
Childhood Illness Group	-.08 (.43)
Step 3	
Childhood Illness Group X Trait Anxiety	-.14 (.30)
Full Model $R^2$ (p)	.03 (.55)
<hr/>	
Model 2	
Step 1	
Age	.00 (.99)
Gender	.10 (.32)
Step 2	
Childhood Illness Group	-.07 (.48)
Step 3	
Childhood Illness Group X Gender	.18 (.55)
Full Model $R^2$ (p)	.02 (.76)
<hr/>	



**Table 7 Group Differences for Friendship Variables****N = 120**

	Survivors	Controls	Cohen's d	p value
Relationship Satisfaction	29.60	30.75	.33	.15
Relationship Expectations	38.20	39.5	.19	.27
Intimacy	127.50	129.47	.07	.96
Fear of Intimacy	71.46	69.44	.12	.42

*Note.* All analyses controlled for age. Cohen's ds are calculated using the SD of the control group.

**Table 8 Correlation Matrix for Friendship Variables**

	1	2	3	4	5	6	7	8
1. Age	-	-.058	.37**	-.18*	-.02	-.12	-.09	.04
2. Gender		-	-.07	.11	-.20*	-.10	-.41**	.38**
3. Childhood Cancer Status			-	-.11	-.13	-.14	-.04	.06
4. Trait Anxiety				-	-.10	.02	-.07	.15
5. Friendship Relationship Satisfaction					-	.63**	.57**	-.53**
6. Friendship Expectations						-	.51**	-.46**
7. Friendship Intimacy							-	-.60**
8. Friendship Fear of Intimacy								-

---

\* p = .05; \*\* p < .01

**Table 9 Moderation of Childhood Illness Group and Friendship Satisfaction**  
**N = 119**

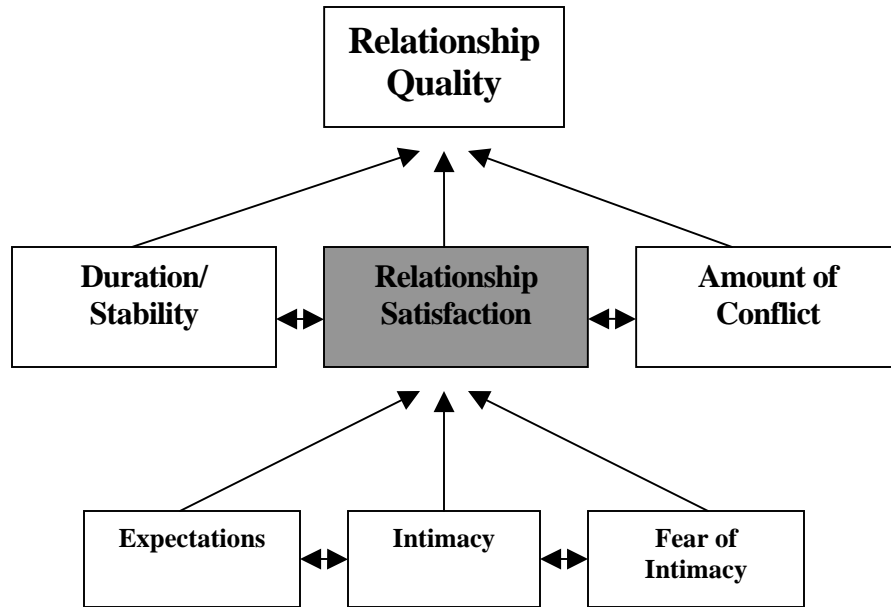
	B (p)
Model 1	
Step 1	
Age	-.02 (.86)
Trait Anxiety	-.10 (.28)
Step 2	
Childhood Illness Group	-.13 (.18)
Step 3	
Childhood Illness Group X Trait Anxiety	-.27 (.06)
Full Model R <sup>2</sup> (p)	.06 (.15)
Model 2	
Step 1	
Age	.02 (.84)
Gender	-.22 (.08)
Step 2	
Childhood Illness Group	-.17 (.54)
Step 3	
Childhood Illness Group X Gender	.07 (.95)
Full Model R <sup>2</sup> (p)	.06 (.11)

**Table 10 Qualitative Interview Participants' Demographics and Illness and Treatment Variables,  
N = 18**

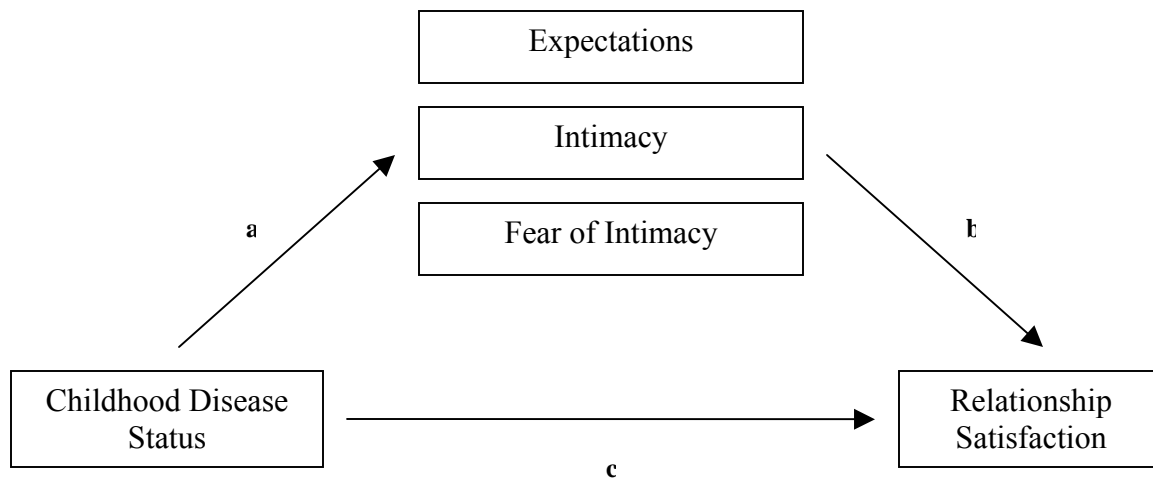
	Mean or %
Age	M = 21.56 (range 19- 25)
Marital Status	
Single	88.89% (n= 16)
Married	5.56% (n = 1)
Divorced	5.56% (n = 1)
Currently in a Relationship	66.67% (n = 12)
Number of relationships in the last five years	M = 2.33 (range 1-4)
Diagnoses	
ALL	27.8% (n = 5)
Wilm's Tumor	22.2% (n = 4)
Hodgkin's Lymphoma	11.1% (n= 2)
Osteogenic Sarcoma	11.1% (n = 2)
Other	27.8% (n = 5)
Age of Diagnosis	M = 7.40 years (range 2-15)
0-5	44.4% (n = 8)
6-11	27.8% (n = 5)
12 and over	27.8% (n = 5)
Time off Treatment	M = 13.83 years (range 6-22)

	Mean or %
Treatment Intensity	
Mild	11.1% (n = 2)
Moderate	55.6% (n = 10)
Severe	33.3% ( n = 6)

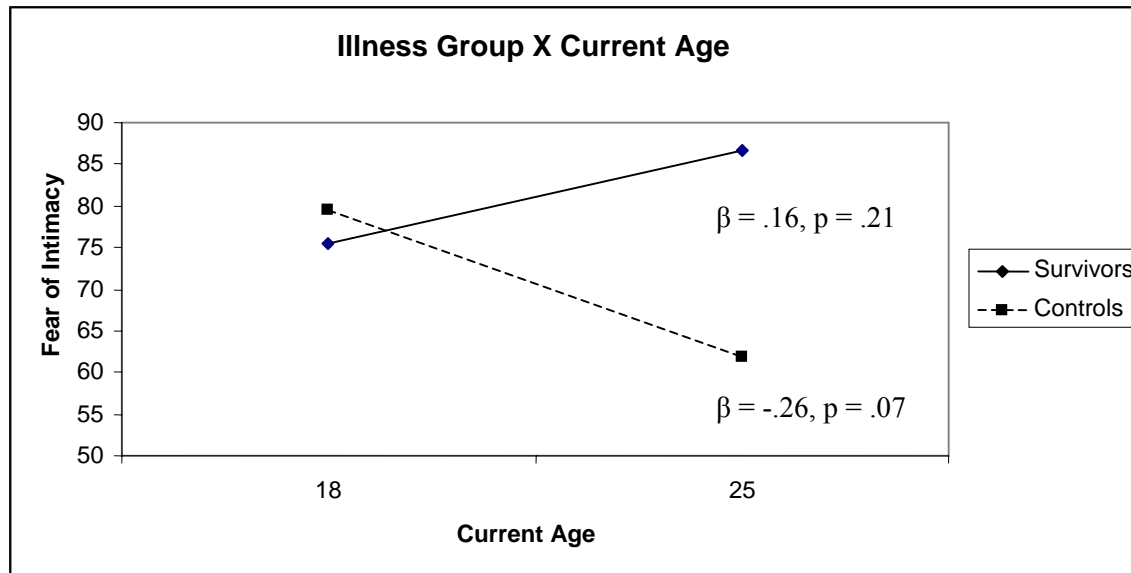
## APPENDIX D: Figures



**Figure 1** Model of Relationship Quality



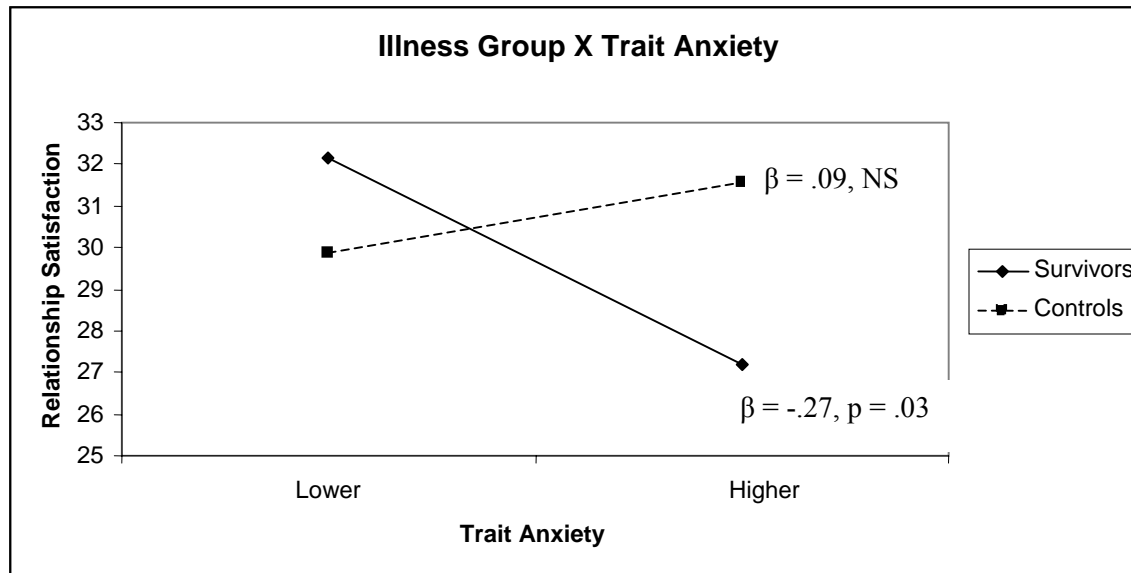
**Figure 2** Mediation of the relationship between childhood disease status and relationship satisfaction by expectations, intimacy, and fear of intimacy



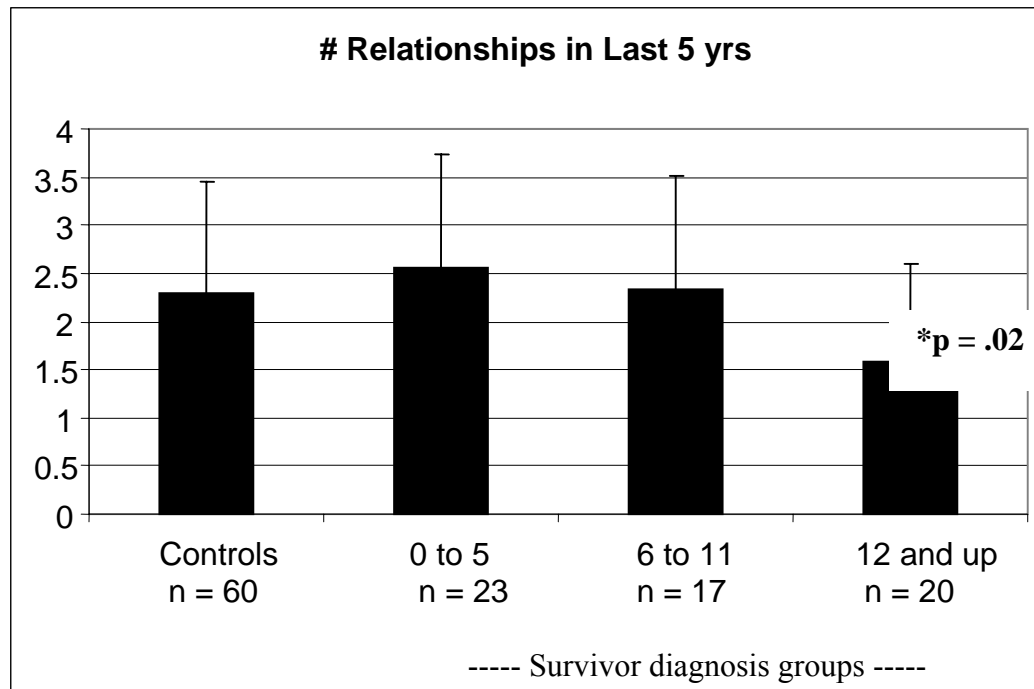
**Figure 3** Interaction of childhood illness group and current age in the prediction of fear of intimacy in a romantic relationship

N = 120

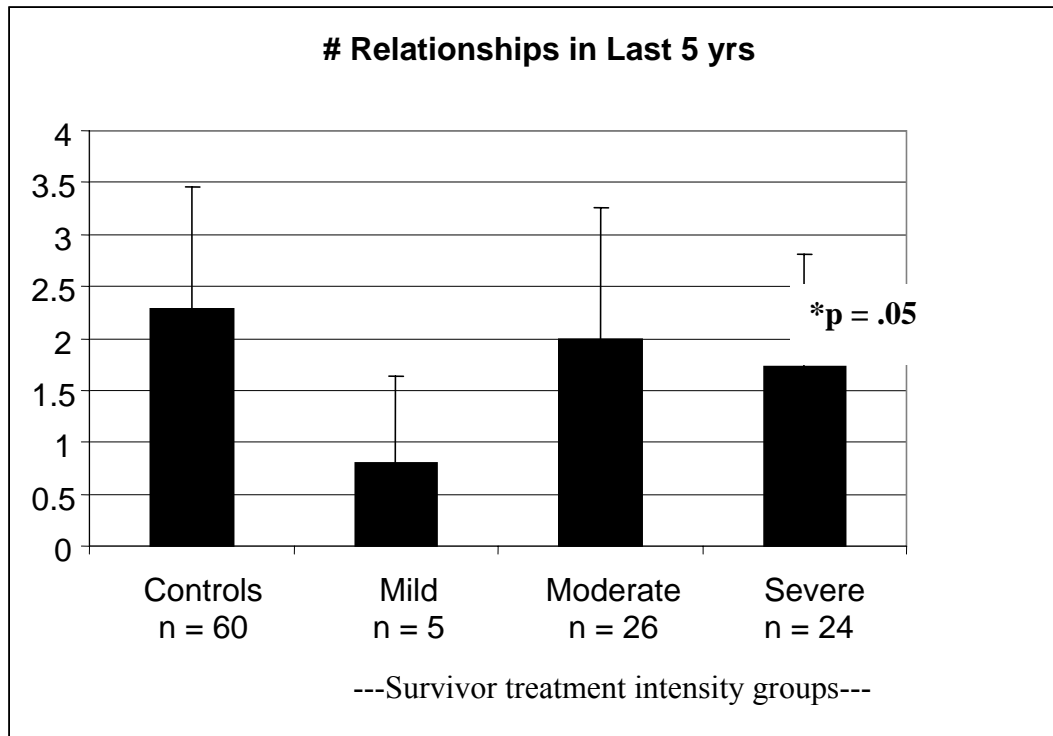




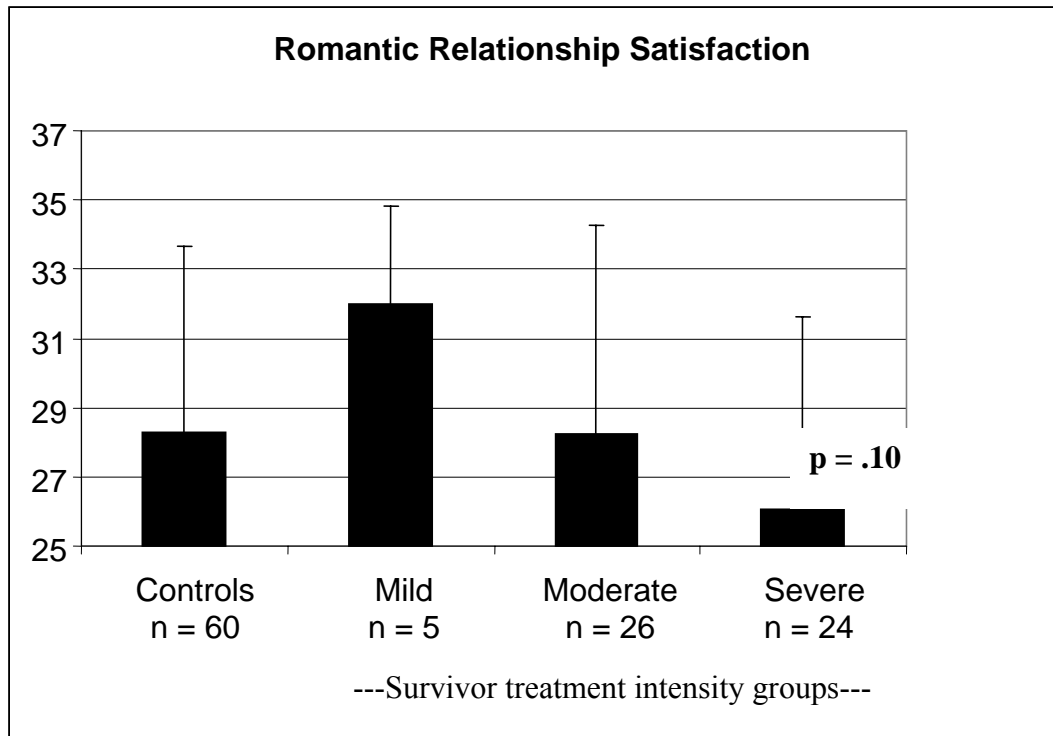
**Figure 4** Interaction of childhood illness group and trait anxiety in the prediction of friendship satisfaction  
N= 118



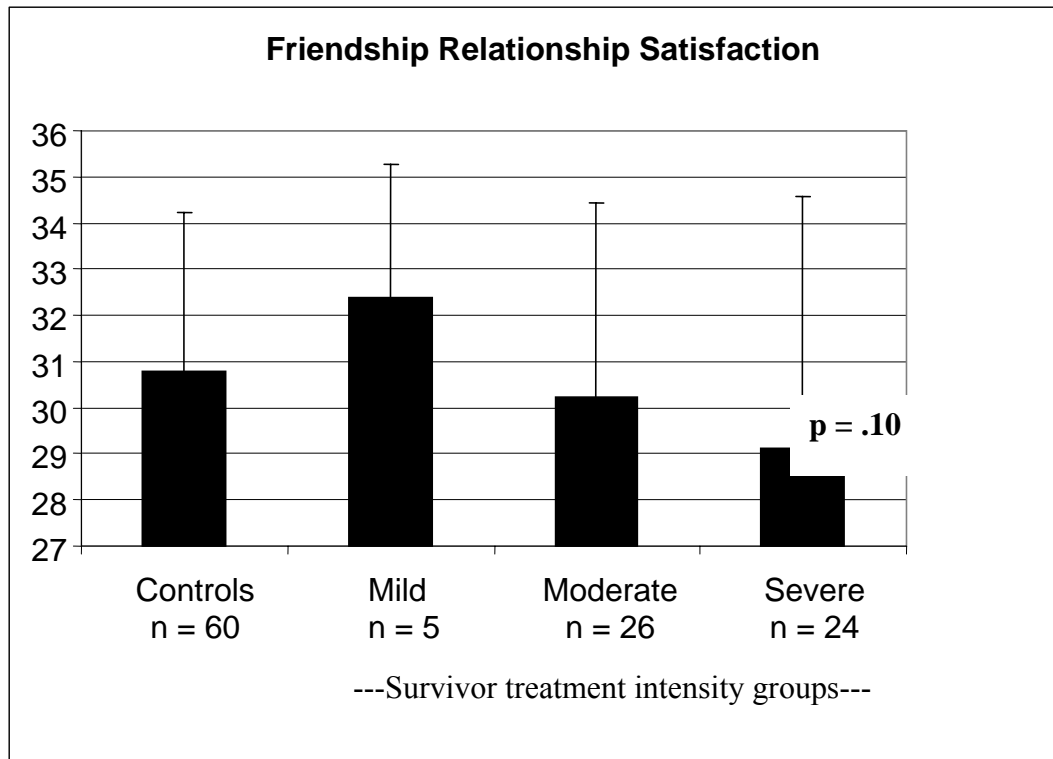
**Figure 5** Number of relationships in the last five years for controls and age of diagnosis survivor groups  
N = 120



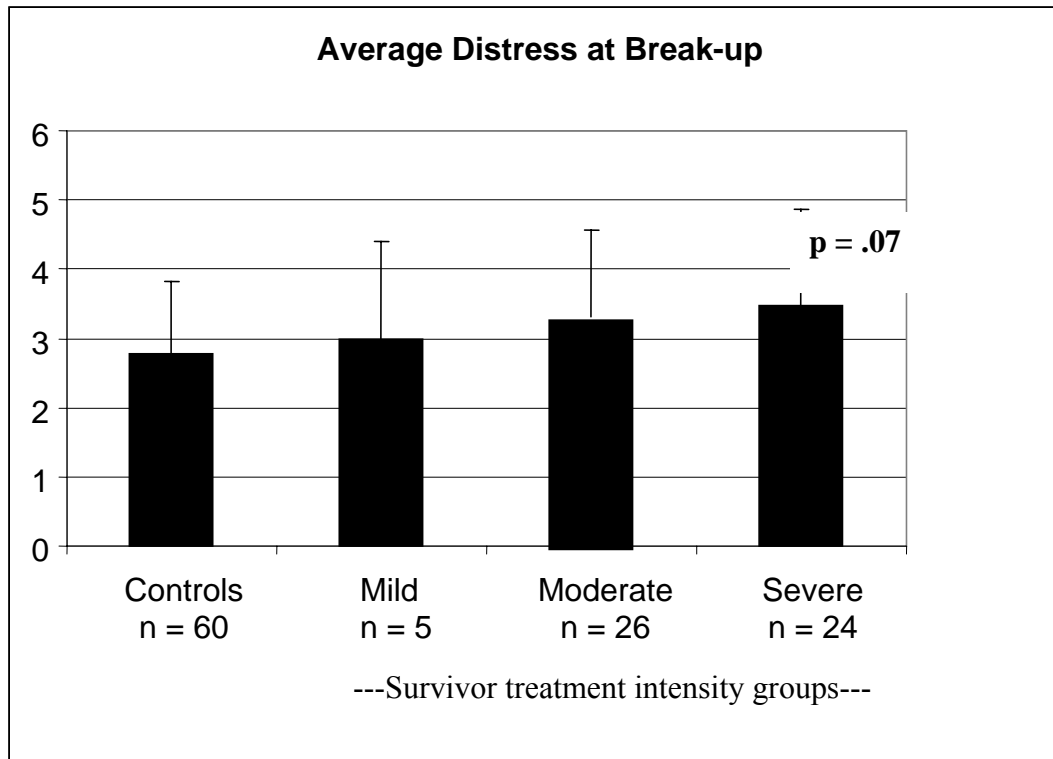
**Figure 6** Number of relationships in the last five years for controls and treatment intensity survivor groups  
n = 115



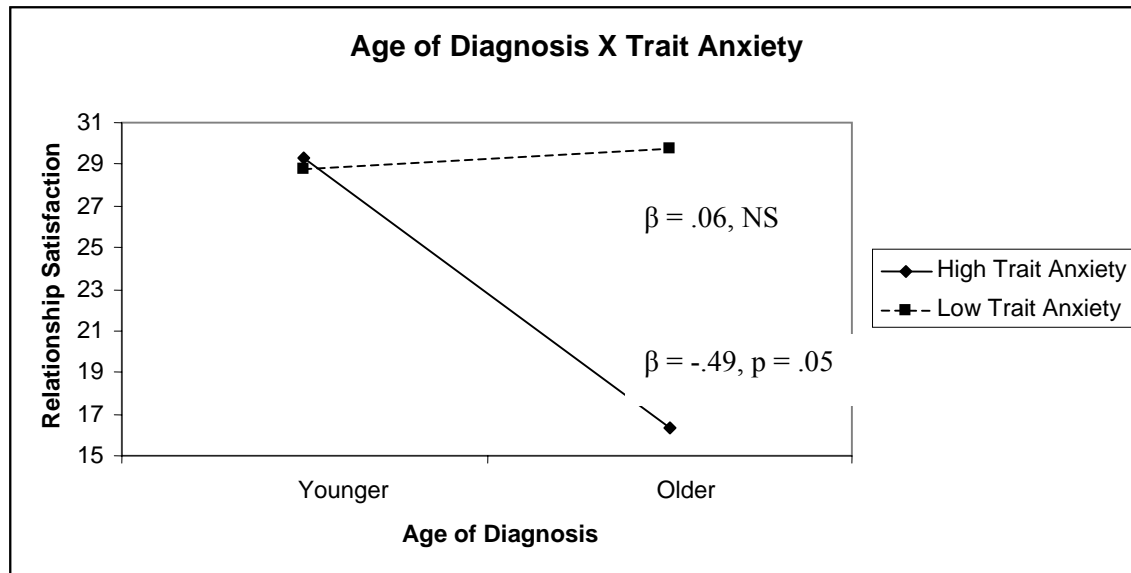
**Figure 7 Romantic relationship satisfaction for controls and treatment intensity survivor groups**  
**N = 115**



**Figure 8** Friendship satisfaction for controls and treatment intensity survivor groups  
N = 115

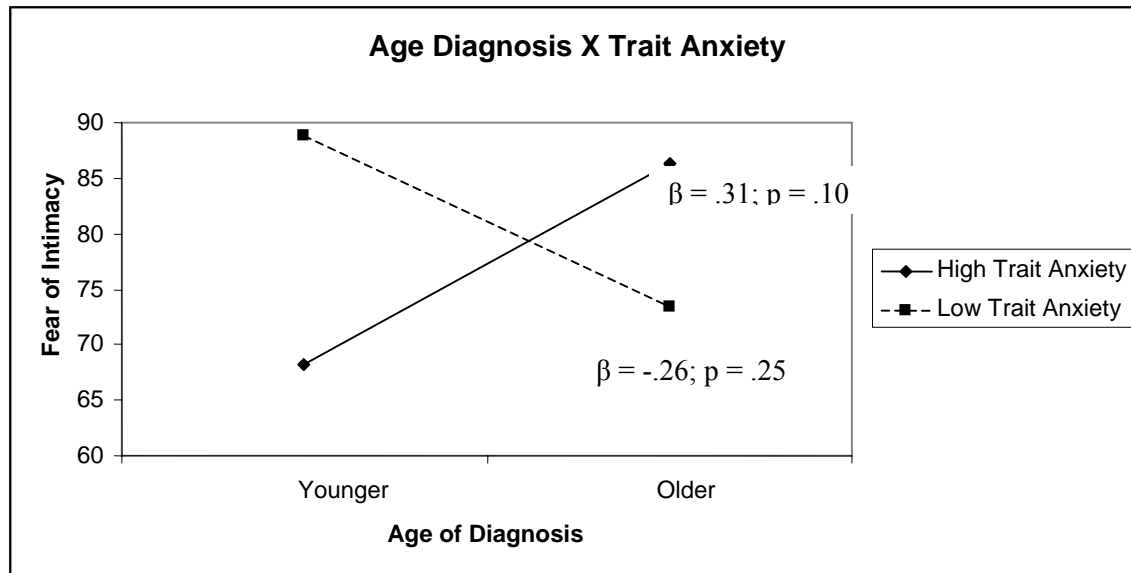


**Figure 9** Average level of distress at relationship end for controls and treatment intensity survivor groups  
N = 115



**Figure 10** Interaction of age of diagnosis and trait anxiety in the prediction of romantic relationship satisfaction within the survivor sample

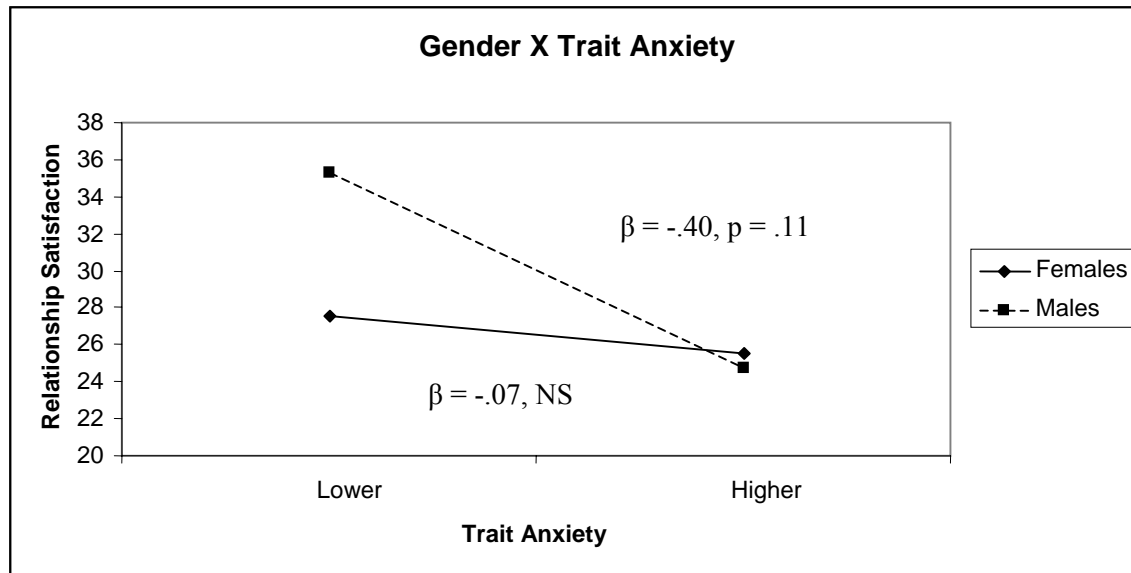
**n = 59**



**Figure 11** Interaction of age of diagnosis and trait anxiety in the prediction of fear of intimacy within the survivor sample

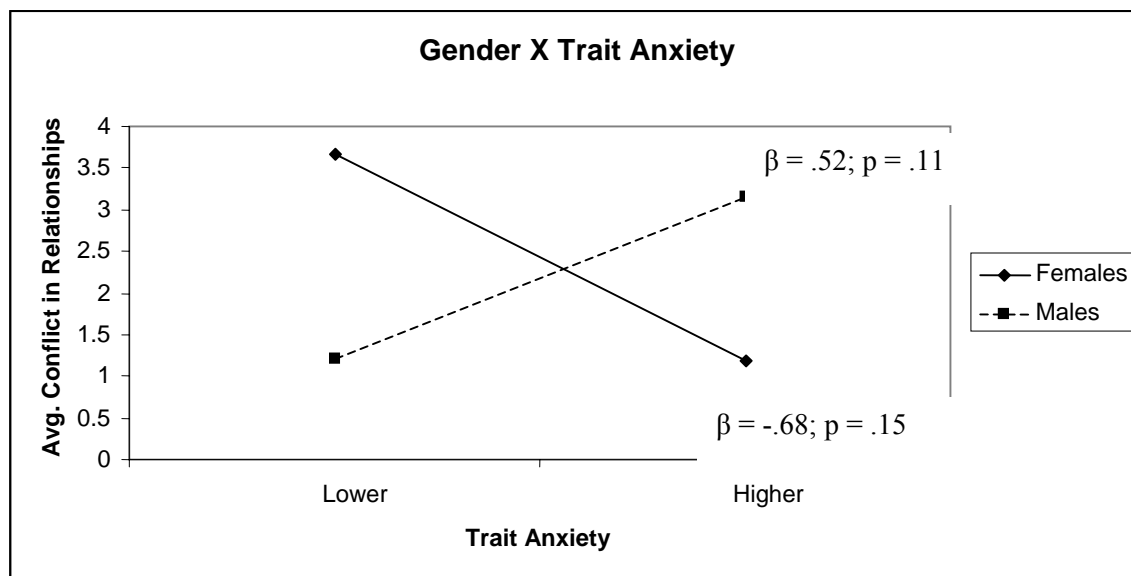
**n = 59**





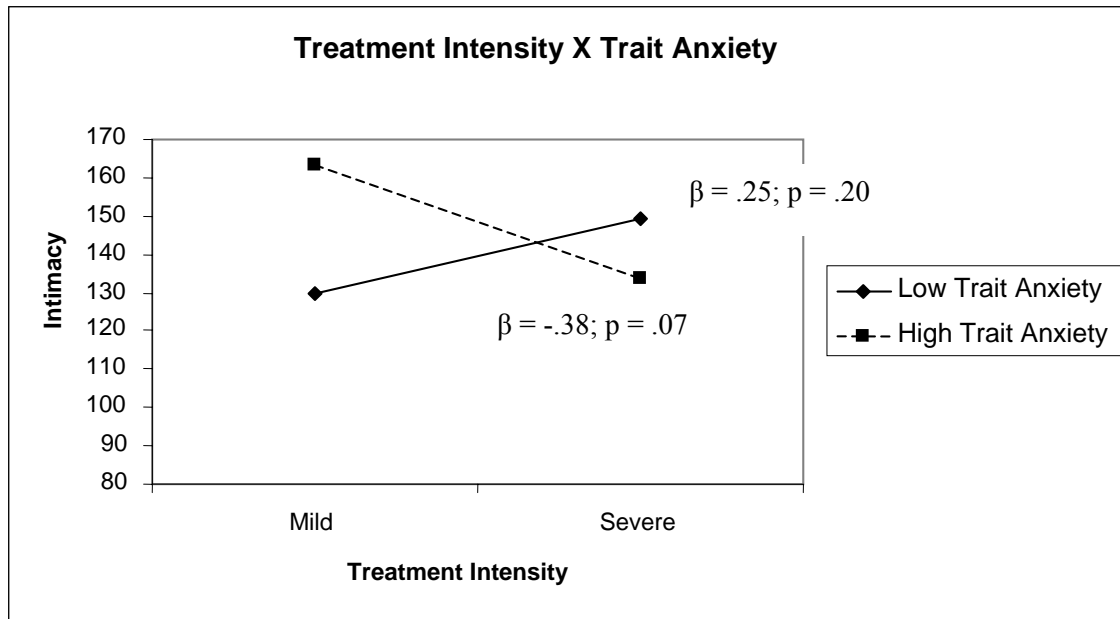
**Figure 12** Interaction of gender and trait anxiety in the prediction of romantic relationship satisfaction within the survivor sample

**n = 59**



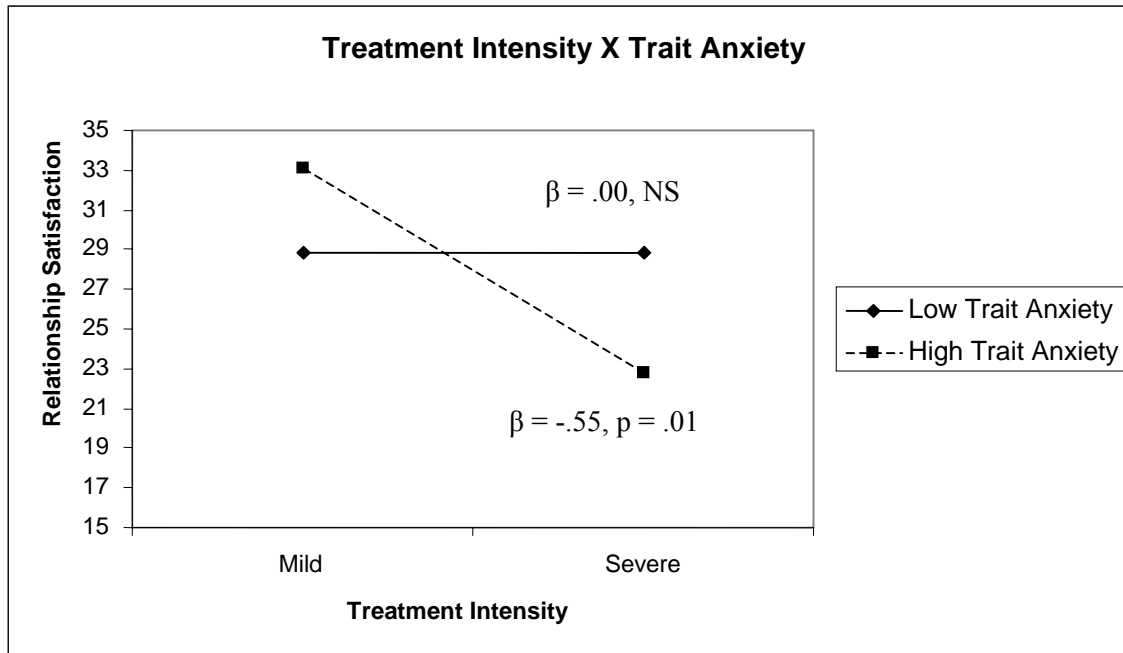
**Figure 13** Interaction of gender and trait anxiety in the prediction of conflict in romantic relationships within the survivor sample

**n = 59**



**Figure 14** Interaction of treatment intensity and trait anxiety in the prediction of intimacy within the survivor sample

**n = 54**



**Figure 15** Interaction of treatment intensity and trait anxiety in the prediction of romantic relationship satisfaction within the survivor sample

n = 54